



**Exploring Reasons for Declining and Withdrawing
from Non-invasive Ventilation among Motor Neurone
Disease Patients: An Interpretative Phenomenological
Analysis**

Thesis submitted in accordance with the requirements of
the Liverpool Hope University
for the degree of Master of Philosophy
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November 2010

Acknowledgements

I would like to dedicate this thesis to my family, who made it possible for me to study in the UK. Their unreserved love and instruction based on their Christian faith have always encouraged me and helped me to get to where I am now. It has been especially appreciated when I was going through a difficult time.

I would also like to thank the Motor Neurone Disease Association for their sponsorship which enabled me to complete this study.

Thanks also to Dr. Robert Angus, Professor Carolyn Young, Dr. Bizwajit Chakrabarti, and Dr. Everard Thornton, who provided this opportunity for me to be involved in their research project.

I would also like to give special thanks to my supervisors Dr. Carl Williams and Dr. Rosanna Cousins for their time and advice.

Special thanks must be reserved for Dr. Robert Angus who kindly offered to help with checking my English despite his busy daily routine. I also would like to thank him for mentoring me with patience and believing in my ability to complete this work which has helped me to think positively and keep trying.

I am also grateful for Juliet Port's contribution to modify this thesis.

Abstract

Objectives: The aim of this study was to understand why some individuals with motor neurone disease (MND) withdraw from non-invasive ventilation (NIV), which has been acknowledged to be an effective treatment for this incurable disease. This study was conducted in response to the unexpectedly high rate of declining and withdrawing from NIV treatment discovered by a bigger study which had been conducted at the Walton Centre for Neurology and Neurosurgery (WCNN) and University Hospital Aintree (UHA).

Methods: A qualitative approach using a semi-structured interview was conducted with ten individuals (male=8) who declined or withdrew from NIV treatment. The age of the participants was between 64 and 79 (mean age=68). Seven participants had multiple interviews and the interviews used for analysis were chosen for the richness of the data in terms of reasons for their decision making regarding NIV. A phenomenological approach using interpretative phenomenological analysis (IPA) was employed to explore their accounts of their experiences.

Findings: Four overarching themes were identified as a result of analysis: preservation of the self, personal perception of intervention with NIV, negative experience with the healthcare services, and not needing NIV. The analysis indicates that changes brought about by the illness could have a negative impact on their perception of themselves, consequently affecting their decision over NIV use. It was also found that NIV may generate fear, which was often observed to form a negative belief about it, leading to a rejection of NIV due to a sense of the loss of control over the machine. A poor impression of the healthcare service was perceived to have impact on participants' willingness to engage with the hospital in consideration of NIV establishment. The data also shows that individuals' understanding of their condition influences their perception regarding their need of NIV. Even though these four themes were found to explain different aspects of non-engagement with NIV, further analysis identified the fundamental issue underlying these concepts: perception of self.

Conclusions: In this thesis, the self represents the sense of autonomy, dignity and quality of life. It was these aspects of the self which participants were trying to maintain by non-engagement with NIV. Therefore, the findings suggest that it is important to detect the underlying reasons for the NIV use as they are likely to have an impact on their general sense of security of the self. Such an approach is primarily hoped to improve the well-being of patients which in turn may encourage them to use NIV.

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CHAPTER 1

Introduction

1.1 Background

This study was designed as part of a bigger project being undertaken at the Walton Centre for Neurology and Neurosurgery (WCNN) and University Hospital Aintree (UHA). The main project was concerned with the experience of non-invasive ventilation (NIV) use among motor neurone disease (MND) patients, their caregivers, and professional carers. The study was designed as a longitudinal study where patients and their carers were followed up every three months for up to three years from the time of referral until the research was terminated or their death. The main focus of the study was to find out how patients' perception of NIV changes over time as the illness progressed. It was also thought that their caregivers may see their own opinion of the ventilation change as their involvement with the patient and their care may become more demanding as the illness progresses and the patient tends to use the ventilation more in the later stage of the illness; which may consequently affect their lives. The professional carers were included in the study to understand their experience of looking after MND patients with NIV and if this experience altered how they perceive NIV treatment.

The main research was initially being carried out by another researcher, from whom some of the patient cohort was handed over to me along with details of the recruitment and collected data. Out of ten patients reported on in this thesis, seven were recruited from the previous researcher five of whom had already deceased before my involvement in the study. The process of handing over involved shadowing the other researcher and role-plays, anticipating the real setting. I also attempted to familiarise myself with the participants and their conditions by consulting their case notes. In this thesis, a total of 13 interviews were used for analysis, 8 of which were conducted by the previous researcher. Further discussion of how the data from the previous researcher was handled can be found in chapter 4.

1.2 Purpose of the study

Thirty percent of participants in a bigger study who were offered NIV treatment declined or withdrew. This research was conducted to find out underlying reasons for withdrawal from NIV treatment which is offered to patients with MND. Therefore, the purpose of this study was to understand a patient's experience and decision making processes around an offer of NIV as part of treatment of MND. It was thought that the study would give insight into the fundamental concerns patients have which affects their decision regarding the use of NIV. The findings of the study will hopefully help professional carers to understand the event from the patient's point of view.

1.3 Medical perspective on MND

Motor neurone disease (MND) is an incurable rare neurodegenerative illness affecting upper and lower motor neurones. There are two types of MND, familial and sporadic MND; there is a significantly higher incidence of sporadic cases (Mitchell and Borasio, 2007). Although the clinical representation of the type is not distinguishable between the two (Phukan and Hardiman, 2009), an earlier onset has been found in familial MND (Moore *et al.*, 2008).

The aetiology of MND remains unknown with a few exceptions of genetic factors found in familial MND (Al Chalabi and Leigh, 2000; Hadano *et al.*, 2001). In contrast to familial MND, the finding of genetic factors in sporadic MND remains inconsistent. Apart from genetic factors, some environmental factors, certain occupations, and physical factors have been reported to be risk factors (e.g. smoking or military service) yet again without consistency (Mitchell and Borasio, 2007). While an epidemiological survey, comparing the incidence rate over time, reports a recent increase in incidence, Beghi and their colleagues (2006) attribute this increase to a better diagnostic assessment of the disease. Generally, the incidence of MND is known to range from 0.6 to 2.6 per 100,000 populations (Chancellor and Warlow, 1992; Cronin *et al.*, 2007) and there is an approximate population of 5000 cases in the UK at any time (Moore *et al.*, 2008). The incidence of the illness is positively correlated with age, with the most prevalence between the ages of 55 and 74, and a decline thereafter (Worms, 2001). Although men are known to be more affected than women with the ratio of 1.6:1 (Mitchell and Borasio, 2007), a recent increase in the

incidence among females has been reported and Beghi *et al.* (2006) argue that this may be caused by the change in the lifestyles of women levelling the environmental factor risk with that of men's.

The onset of the illness varies depending on the pattern of involvement of the upper motor neurones (UMN) or lower motor neurones (LMN) and is divided into four different categories: lower limb onset, upper limb onset, bulbar onset, and respiratory onset (McDermott and Shaw, 2008). In terms of lower limb onset, patients may experience difficulty in walking or unsteadiness, foot drop, and heaviness or stiffness in legs (Hankey and Wadlaw, 2008; Moore *et al.*, 2008). Upper limb onset is often seen in the loss of fine hand movements, weakness in the hands and/or the arms, muscle wasting especially in the hands, or fasciculations seen particularly in the large proximal limb muscles (Hankey and Wadlaw, 2008; McDermott and Shaw, 2008). Patients with bulbar onset usually display dysarthria (difficulty in articulation of speech) or dysphonia (difficulty in speaking). Dysphagia, difficulty in swallowing, is often accompanied by dysarthria and more pronounced with liquids than solids (Moore *et al.*, 2008). Respiratory onset is the least common onset, involving orthopnoea and nocturnal hypoventilation resulting in hypercapnia, which causes headaches, and there is associated hypersomnolence, fatigue and other features (Moore *et al.*, 2007; Phukan and Hardiman, 2009). Also, a fronto-temporal dementia occasionally complicates the motor lesions (Phukan and Hardiman, 2009).

There are four different clinical patterns commonly recognised in MND: amyotrophic lateral sclerosis, primary lateral sclerosis, progressive muscular atrophy, and progressive bulbar palsy. The involvement of the deficit in the brain or spinal cord determines the subtype of the illness. The summary for each classification with approximate survival times are listed in Table 1. Even though the typical survival time of the illness differs according to the type of MND, recent studies suggest a slower disease progression in the modern era (Czaplinski *et al.*, 2006). From comparison between current (1999-2004) and historical (1984-1999) time frames, Czaplinski and his colleagues (2006) found slower progression in the current patient group. In response to this trend, they suggest the plausible positive effect of therapeutic intervention and supportive treatment which may somewhat mitigate the aggressive nature of the disease. Alternatively, with modern diagnostic services it may be that milder variants of the condition are being recognised as MND hence the somewhat

more positive outcome in the current patient group. more investigation of this issue is needed.

Table 1: Four Different Presentations of MND and their Characteristics

Presentations	Summary of the presentation
Amyotrophic lateral sclerosis (ALS)	This form is the most common of MND, affecting both UMN and LMN. ALS involves a degeneration of corticospinal tract neurons in the motor cortex, brainstem and spinal cord motor neurons (Hankey and Wardlaw, 2008). Most cases present limb onset, though 50% of the patients eventually develop bulbar symptoms. Median survival is 3-5 years (Phukan and Hardiman, 2009).
Progressive bulbar palsy (PBP)	PBP is more common in elderly women and, similar to ALS, this form of MND also involves both UMN and LMN. The degeneration of two cranial nerves: glossopharyngeal IX and hypoglossal XII (Hankey and Wardlaw, 2008). The former is associated with tastes, somatosensory and some muscle controls used for swallowing, while the latter is related to the control of tongue movements (Crimando, 2005). These cranial nerves originate in the medulla oblongata. 20% of the cases are bulbar and/or pseudobulbar palsy onset with a poorer prognosis of 2-3 years (median) survival (Phukan and Hardiman, 2009).
Primary lateral sclerosis (PLS)	A pure UMN involvement with lower limb often affected first at the time of onset. The complete absence of Betz cells (large pyramidal cells) from layer 5 and decreased pyramidal cells from layers 3 and 5 of the precentral cortex are prominent in this subtype, coexisting with laminar gliosis (excess growth of astrocyte) and shrinkage of any size of pyramidal neurons (Hankey and Wardlaw, 2008). Up to 77% of the cases develop to ALS within 3-4 years. The median survival for pure PLS is 20 years or more (Phukan and Hardiman, 2009).
Progressive muscular atrophy (PMA)	More common in men (men: women= 5:1) with pure LMN symptoms at the onset with some cases developing into ALS at the later stage. PMA features with chromatolysis or the loss of motor neurones of the brainstem and spinal cord (Hankey and Wardlaw, 2008). Common onset is <50 year-old and a median survival of 5 years with a subset of 20 years or more (Phukan and Hardiman, 2009).

1.4 NIV treatment

There is no cure for MND, however, various therapeutic treatments are useful and are offered to patients. These treatments include: pharmacology using the drug riluzole and symptom relieving therapies, nutritional support, respiratory interventions, and physical therapies. A respiratory intervention is acknowledged to be important since most deaths in MND are caused by pulmonary complications (Andrew, 2009; Winhammer *et al.*, 2005). Previously, respiratory intervention among MND patients was available generally by tracheostomy, however, NIV has seen a recent growth in its use and has become a more common treatment in some countries, especially in Europe and North America (Radunovic *et al.*, 2009). NIV improves biological well-being by normalising the level of arterial oxygen and carbon dioxide (Mehta and Hill, 2001) which is low due to respiratory insufficiency (Bourke *et al.*, 2003). As a result, NIV benefits patients with a median survival of more than 500 days (Bourke *et al.*,

2003; Bourke *et al.*, 2006), which exceeds the benefit gained by Riluzole, the sole approved disease modifying drug, of 2-3 months (McDermott and Shaw, 2008). The importance of NIV to the MND patient is such that it was the subject of the National Institute for Health and Clinical Excellence's (NICE) technology appraisal, which was reported in July 2010.

NIV (see Appendix 1 for pictures of available masks) is offered to patients once they display the sign of hypoventilation, which is usually monitored by assessments of spirometry which measures forced vital capacity (FVC). As a standard guideline, the American Academy of Neurology (AAN) recommended NIV intervention once the predicted value of FVC drops below 50 % (Miller *et al.*, 1999). However, more recent studies report that earlier NIV intervention benefits MND patients further. For instance, Lechtzin *et al.* (2007) found that the median survival time from diagnosis was 329 days longer for patients who were established with NIV when the predicted value of FVC was higher than 65%. As suggested by Miller *et al.*, (2009), this increased benefit observed in patients who started NIV earlier than recommended by AAN is likely to be reflecting the insensitive nature of FVC measurement. Indeed, FVC% was found to be poorly correlated with early respiratory symptom (Jackson *et al.*, 2001). In comparison with FVC, nocturnal pulse oximeter enables the clinician to detect respiratory muscle weakness (Chetta *et al.*, 2007) at an early stage by measuring the value of nocturnal oxygen saturation which is predicted by inspiratory muscle weakness. In their study, Jackson *et al.* (2001) argue that overnight oxygen saturation measured by nocturnal pulse oximeter is the most sensitive measurement to detect pulmonary insufficiency: the cumulative minute spent <90% of overnight oxygen saturation was the most sensitive indicator of pulmonary insufficiency, whereas the mean rate of FVC% for those desaturated patients was still 77%. In view of these findings, NICE guidance suggests a combination of assessments, such as with oxygen saturation, rather than using FVC as a sole assessment for pulmonary functioning. The sensitivity to respiratory insufficiency enables healthcare professionals to detect the need of NIV sooner which subsequently improves compliance with NIV (Pinto *et al.*, 2003). After the establishment of NIV, its use for a minimum of 4 hours has been reported to be crucial to beneficial outcomes (Phukan and Hardiman, 2009). A weaning of NIV is pragmatically advised by healthcare professionals and usually indicates a change in the goal of treatment: from management and alleviation of symptoms to management of dying.

NIV is widely recognised to improve patients' quality of life (Bourke *et al.*, 2006; Sundling, 2009) and is thus widely recommended as a standard treatment (Andrews, 2009; Phukan and Hardiman, 2009). However, this 'quality of life' is a generalised concept and measured quantitatively thus falling short of reflecting a detailed idiographic account, especially of those categorised as 'abnormal'. Furthermore, the meaning of the concept of 'quality of life' may be questioned as there is no consensus on its definition (Lipsman *et al.*, 2007). Previous studies have reported the benefit of NIV, yet these quantitative measures do not fully reflect the idiographic experience or patient's experience of encounter with NIV, which are the main concerns of this study. As seen in the development of the NICE guidance (2010), there has been a significant lobby to ensure NIV is available to patients and a growing expectation that it is offered, but there is little investigation into the experience of patients as they consider using this intervention.

1.5 Treatment compliance

Generally, previous studies on NIV have mainly focused on benefits of the treatment and these benefits were often measured by a mean of comparison between NIV users and non-users (Lo Coco *et al.*, 2006; Mustafa *et al.*, 2006; Silvak *et al.*, 2001). While these studies acknowledge that NIV is not always tolerated or accepted, little attention has been paid to exploring the factors leading up to the decision to use NIV, thus, any reason for withdrawal from the treatment remains unknown.

Non-compliance to treatments is not limited to NIV use in MND patients. On the contrary, it is widely acknowledged in other illnesses. Many studies have attempted to understand determinants which lead to such an outcome with the majority of studies looking into reasons for compliance of drug treatments. In their review, Vermeire *et al.* (2001) identify different types of non-compliance, some intentional and some unintentional, in relation to medication treatment. According to their review, there is generally 30-50% of non-compliance regardless of diagnosis, prognosis or setting, and they report that this non-compliance may occur at a different stage of the illness. With regard to determinant factors for non-compliance, Vermeire *et al.* (2001) argue that it is complex with no absolute determinant, yet patients' beliefs about treatments was identified as the most prominent contributing factor

together with other less salient factors, such as no perceived symptom of illness or fear of adverse effects of the treatment. Similarly, Ross and their colleagues (2004) observed treatment beliefs to be influential in determining compliance among individuals with hypertension. Furthermore, they argue for a connection between their perception of treatment and beliefs about their ability to control their symptoms: poorer compliance was perceived in individuals with low self-belief in their ability to control their condition. It was also reported that the compliant individuals perceived the treatment as a cure rather than a way to control symptoms which indicates that individuals differentiate 'cure' from 'control' (Ross *et al.*, 2004), suggesting that their treatment compliance is affected by the perceived curability of the illness.

These previous studies indicate the complexity of treatment compliance and for this reason, some prefer to replace a term 'compliance' with 'adherence' to imply patients with more autonomy and independence who have their unique characteristics and are able to both identify and pursue their own goal (Lutfey and Wishner, 1999). Based on this understanding that individual's independent evaluation of the situation affects their compliance/adherence to treatments, it may be suggested that their preference of treatment can be used as an indicator of their response to the treatment and this can be observed in longitudinal studies which followed the preference and a trajectory of care. For instance, Albert and his colleagues (2009) found MND patients who did not favour tracheostomy also ceased to take medications towards the end of their life. Likewise, Albert *et al.* (1999) found that the baseline preference of treatments predicted not only the trajectory of their treatment, but also an earlier intervention with the treatments. These studies thus suggest a positive influence of their preference on their actual treatment and presumably compliance/adherence. Therefore, as the term 'adherence' implies, individuals' perception appears to be vital in how they may respond to treatments.

1.6 Significance to the researcher's position

Even though previous studies do not provide sufficient reasons for declining or withdrawing from NIV, some studies have explored the experience of people already established with NIV and identified unfavourable features of NIV (Lemoignan and Ells, 2010; Lindahl *et al.*, 2005). Therefore, it may be assumed that these negative factors are present at the time of referral to NIV service and that they later become

determinants when patients consider accepting and the use of NIV. In order to investigate the reasons for non-adherence, however, separate assessment and evaluation of each case is crucial, since the “lived experience” of each individual varies, affecting the trajectory of the decision-making process.

As will be explained in the following chapter, an interpretative phenomenological analysis (IPA) would enable me to investigate the reason for NIV withdrawal in a manner that allowed each individual case to be examined carefully and in depth to capture the individual and personal factors, while also allowing me to examine the overarching concerns common to different individuals. Important aspects of IPA are interpretation and phenomenology. It is a method used in order to understand how people make sense of their experience. Hence, interpretation of the account is inevitable, whereby my previous knowledge and experience interweaves with the participants’ accounts. Although it was not possible to totally omit my preconceptions, an attempt to bracket them out was made as with reflection I became aware of them so that my interpretation was as faithful as possible to the given accounts. It is also essential that readers are aware of my position so that my interpretation can be evaluated by them. Therefore, I describe my position before I move onto the next chapters.

Although my aim was to understand why people withdraw from NIV treatment, which implies plausible negative aspects related to the treatment, I was also aware that I valued the benefits which NIV can contribute to patients’ lives especially in terms of improvements in energy levels for daily activities and the survival outlook. My views were based on my witnessing other MND patients who have positive experiences with NIV and knowledge of respiratory functioning of how NIV can improve the adverse event brought about by MND. Also, it is arguable that my own experience of trying NIV without any adverse feeling towards the machine affected my initial perception of the treatment. Therefore, it may be said that I failed to experience how the same event may be experienced by other individuals. Furthermore, there may be both physical and psychological differences between my experience of NIV as a healthy individual and those of individuals with the terminal illness. Finally, my view might have been influenced by how death is treated in this society: death is feared for its threat to an existential aspect, process and the consequence of dying (Nyatanga, 2005). It can be argued that living in this society had unconsciously formed my perception that a prolongation of life is generally a good thing.

All considered, the use of IPA in this particular setting would enable me to understand the participants whose experiences are different from these who hold positive views on NIV. The approach would allow me to address individuality while giving me an opportunity to also extend it to more general claims.

1.7 Summary

Medically, NIV is acknowledged to be one of the most beneficial treatments for individuals with MND, whose condition continually deteriorates over time.

Psychologically, however, people display different reactions to the treatment. Most MND patients accept NIV, while others decide that it is not for them. Previous studies have been heavily concerned with the reported benefits of NIV and have neglected negative aspects of the treatment leading to withdrawal. It was felt that a study to explore the reasons for withdrawal needed to be conducted so that these people's voices could be heard, which would in turn hopefully provide a more balanced view of NIV for future practice. It was also hoped that an understanding of idiographic experience would help healthcare professionals to provide the best care for each individual.

CHAPTER 2

Literature Review

2.1 Introduction

There have been a good number of qualitative studies conducted within health psychology to understand what it is like to live with illnesses and how this differs between people. Qualitative methodology allows researchers to study the complex health related issues by looking at the links between physical changes, cognition, and a verbal presentation of the status (Smith, 1996). These studies enable us to gain insight into the impact of, for instance, diagnosis (Dickson *et al.*, 2008; Hubbard *et al.*, 2010; Irvine *et al.*, 2009; King *et al.*, 2009; Smith and Osborn, 2007; Snelgrove and Liossi, 2009), life with illness (Brown and Addington-Hall, 2008; Hubbard *et al.*, 2010; King *et al.*, 2009; Knight *et al.*, 2003; Smith and Osborn, 2007), and inner changes caused by illness (Dickson *et al.*, 2008; Hubbard *et al.*, 2010; Smith and Osborn, 2007; Snelgrove and Liossi, 2009). These studies inform us that illness can cause a dramatic change not only biologically, but also psychologically.

For this study of non-invasive ventilation in MND we were interested in individuals and their experiences. A literature review on qualitative studies was undertaken. Topics such as experience of illness and decision making were searched for together with breathlessness, which is a particular symptom leading to the offer of NIV; this was suggested by the collaborating healthcare professionals. This chapter outlines the literature review conducted and key terms relevant to my research questions are presented.

2.2 Literature search

Important aspects claimed by Smith *et al.* (2009) in respect to literature reviews within IPA may be first noted. They argue that literature reviews can, on the one hand, cast light on unexplored areas as well as providing researchers some understanding of the people in the same situation. On the other hand, however, they alert researchers to the fact that it can seed certain ideas in researchers' minds, forming preconceptions. Thus, IPA researchers need to be cautious during this period and to attempt to ensure

potential preconceptions are ‘bracketed off’ (Smith *et al.*, 200). Keeping this in mind, the literature search was carried out and key terms were identified.

Relevant literature was identified by searching computerised databases including EBSCOhost, reference lists of searched articles, and Google scholar search engine. The terms used to identify articles were ‘phenomenology’, ‘interpretative’, ‘qualitative’ and ‘interviews’ for previous qualitative studies, while ‘lived experience’, ‘illness’ and ‘coping’ were used to understand the impact of an illness. The terms ‘decision making’, ‘treatment’ and ‘preference’ were searched to explore how decisions are made following a diagnosis and ‘ventilator’ and ‘breathlessness’ were looked for to examine if there is any other element involved in decision making for a respiratory complication. ‘Motor neurone disease’ and ‘amyotrophic lateral sclerosis (this term is synonymously used in some countries for MND)’ were also searched to understand general aspects of the illness.

I only included papers which employed qualitative methods most of which used phenomenological approaches. One systematic review paper on qualitative studies was also included to confirm the generality of findings rather than to use it as its own account. Papers were excluded if their focus was on children, experience of caregivers, or retrospective accounts by caregivers on patients, unless there were relevant accounts of adult patients.

2.3 Key topics

The literature indicates and confirms that biological well-being affects psychological well-being. Individual perception and the degree of their awareness and acceptance of the changes brought about by illnesses then determine how people respond to the changes and their choice of available treatments. Additional aspects uniquely associated with NIV treatment were also recognised from the previous research.

Identified key themes were: diagnosis, living with changes, decision making, and perceptions of NIV. These key terms were chosen in order to understand the context of participants’ experiences and how these may have influenced their decision regarding NIV use. The key terms and summary for each term are presented in Table 2.

Table 2: Key Terms and Their Summary

Terms	Summary
1. Diagnosis	Internal reactions to the diagnosis
2. Living with changes	Coping and adaptation
3. Decision making	Preference of care
4. Perceptions of NIV	Evaluation of relief and burden

2.4 Literature review

2.4.1 Diagnosis

There have been a good number of qualitative studies done to explore the impact of diagnosis and how changes are experienced by individuals. The previous studies argue that an experience of physical change is not a straightforward process, but rather a dynamic one: it affects people’s self perception, emotional feeling, and their sense of mortality. In addition, the previous studies also indicate that these changes are experienced within a context of social interaction. Contribution from qualitative studies in this area has provided insight into individual experience of receiving a diagnosis.

Biological changes alert people to seek help from healthcare professionals where they usually receive diagnosis. Although the physical condition may be labelled and settled with a new term, previous studies reveal a complicated pathway which inner status goes through as a result of physical changes, such as denial of the situation and diminished confidence (Irvine *et al.*, 2009). One study investigated the experience of people with lower back pain to understand how pain affects people’s psychological condition (Snelgrove and Liossi, 2009). Among those participants, pain was perceived as a growing threat which gradually takes over their body whereby patients felt a sense of loss. Thus, the pain may be understood as an invasion to their control over their body. Presumably due to this sense of the loss of control, people with physical restrictions have also been found to experience a loss of independence (Dickson *et al.*, 2008). These losses, created by physical restriction, were then observed to contribute to their sense of loss/change in their identity, which simultaneously affected their self-esteem (Dickson *et al.*, 2008). The findings of Snelgrove and Liossi (2009) among individuals with lower back pain also agree with the outcome of damaged self-esteem as a result of the loss of control over their body. Therefore, it can be argued that self-esteem may be damaged following the restriction to the body's ability to perform, as it impacts on their idea of the self. The sense of

changed identity has been reported to be a major challenge to coping and it was indeed expressed by one patient with lower back pain that this was harder to cope with than the physical change (Smith and Osborn, 2007). In addition, the sense of the loss of control and independence have been linked with the emotional outcomes, such as anger and embarrassment (Dickson *et al.*, 2008). It should also be noted that the previous studies also observed that not every ill individual finds the biological change threatening to their identity, some see it as a more simple physical and psychological disruption (Dickson *et al.*, 2008; Hubbard *et al.*, 2010; King *et al.*, 2009).

The loss associated with the illness and the negative emotional reactions, such as sadness and despair, following the diagnosis have also been acknowledged among individuals with MND (Foley, *et al.*, 2007; Hugel *et al.*, 2006; King *et al.*, 2009). A study of newly diagnosed patients (3-6 months) showed that they experienced frustration and the loss of control which were generated as a result of physical deterioration, which in turn affected their self-esteem and self-confidence (Hugel *et al.*, 2006). They also indicated the complexity of the issue of control: patients generally appreciated the daily help they received from other people, yet the help was sometimes seen to violate their control due to their dependency. Because of the loss of independence and control of the body, the notion of 'normality', which implies their previous standard of life, may be abandoned. Nonetheless, patients may attempt to stay as normal as possible in abnormality: called 'dynamic normality' by Brown (2003).

In addition to these recognised reactions to the changes brought about by illness, additional concerns may be discussed in terms of MND as a terminal illness. In consideration of this aspect, it seems reasonable to consider that other people with different fatal illnesses, such as certain types of cancer, have similar concerns when faced with their diagnosis. In this aspect, a concern over mortality expressed by people with cancer may be noted (Hubbard *et al.*, 2010). This concern seems to be expressed by manifesting their feeling of a total negation of their existence following the diagnosis. Similarly, MND patients also expressed the existential threat and fear of death, which is accelerated by the loss of control as a result of physical deterioration (Bolmsjo and Hermeren, 2001; Brown, 2003). Furthermore, studies found that the sense of mortality is indicated/revealed by breathlessness because of its manifestation and an experience of breathlessness has also been found to trigger fear and uncertainty in MND patients (Booth *et al.*, 2003; Gysels and Higginson, 2010).

Another common phenomenon identified to take place after diagnosis was an appraisal of the situation by a comparison with previous self or others in order to make sense of the situation (Harman and Clare, 2006; Knight *et al.*, 2003; Williams *et al.*, 2004). While comparison with the previous self may highlight the patient's ever-changing situation which for some means futureless (Knight *et al.*, 2003), comparison with others whom they consider to be in a worse situation may benefit individuals by providing them with a sense of positive aspects to their situation (Williams *et al.*, 2004). As seen in the latter case, the impact of the social interaction appears to be prominent in how an individual perceives themselves with the illness (Dickson *et al.*, 2008; Hubbard *et al.*, 2010; Snelgrove and Liossi, 2009), triggering self-appraisal and seeking reinforcement from other people (Snelgrove and Liossi, 2009). The significance of the social aspects was also observed in individuals with MND, where public image was found to be important in order to maintain self-esteem while physical impairment creates fear of public humiliation (King *et al.*, 2009). These findings seem to suggest that what is perceived to be self is greatly affected by others' perception of the person, or rather a mere belief held by the individual of what other people think of them despite the reality of it. Therefore, it may be argued that self-esteem is founded in the context of social interaction where the standard for the individual performance is assessed by individual's expectation regarding themselves, which is manifested in the social settings. A re-evaluation of their idea of the self may occur after an impairment of the body and this is often seen to be carried out by means of a comparison.

The loss of control of the body may affect an individual's sense of self because of the restriction and inevitable need of help from others. Both identity and self-esteem have often been recognised to become susceptible as a result of the illness. Although there is an inner discrepancy between their expectation of the self and the reality, social interaction appears to have a great impact on how their expectation is formed. In addition to these complexities; trajectory of mind and the sense of existential threat may be added with regard to MND because of the nature of the illness.

2.4.2 Living with changes

In response to the changes caused by illnesses, the discussion of the way people cope with the changes have also been expanded and some different coping strategies have

been found. This section addresses what determines people's adaptation style and how they reflect individual's perception of the illness. I will also discuss whether there is any better coping strategy among the many that exist.

Previous studies report that how individuals cope with subsequent changes due to illnesses, including MND, varies according to their perception of the illness and the degree of acceptance of the changes. For instance, Brown and Addington-Hall (2008) distinguish four different types of coping strategies: sustaining, enduring, preserving and fracturing. The first type illustrates individuals with a positive attitude and with their main focus on symptom control and survival, while the second category describes passive people who quietly suffer and await their departure. The 'preserving' type actively does something to fight against the illness to get the sense of control over the illness, whereas 'fracturing' types display avoidant acceptance and denial of both reality and outlook on life because of their fear and the loss. As illustrated by these different types argued by Brown and Addington-Hall (2008), acceptance and individuals' perception of circumstances are evident in how their coping strategy is constructed. Furthermore, an issue with control, often generated as a result of illness, appears to have an impact on how individuals may be able to adapt to the changes: either an individual sees the illness to be controlling them or the individuals are seen to be in charge of the situation. These adaptation differences then seem to reflect people's adaptation to their identity change, which has also been reported to exhibit some different forms: some individuals have been found to be struggling between their previous identity and the new identity (Hubbard *et al.*, 2010; Smith and Osborn, 2007), others were found to have been resigned to their new identity and passively accepted it (Smith and Osborn, 2007), or some acknowledge changes as disruptions yet perceive no change in their identity (Hubbard *et al.*, 2010).

Among the various coping styles employed by individuals, some positive adaptations to the change have been reported. By positive adaptation, Knight *et al.* (2003) mean the coping style which leads to the sense of liberation through personal and intellectual development. Another study referred to individuals as having a positive coping style if they were able to set new achievable goals, which in return, gave them the sense of regaining their sense of self, improving self-esteem and self worth (King *et al.*, 2009). From these arguments, 'positive adaptation' may be understood as a psychological empowerment in adverse circumstances. While active coping strategies of adaptation to changes benefit the psychological well-being of

patients, a passive style with denial, often to protect their self-esteem, creates a pessimistic view on life (King *et al.*, 2009). However, as King and her colleagues (2009) observed, one's coping style is not static and may differ from time to time with some individuals swinging between the two.

Lastly, another influential factor for active coping style may be suggested: hope. According to Brown and Addington-Hall (2008), hope underpins the positive attitude towards the illness and this hope is usually interpreted as the hope for better symptom management and survival. Congruent with their findings, the significance of hope was shared with physiotherapists (Soundy *et al.*, 2010). They argue that hope is important for motivation and the absence of it could lead to 'falling short of potential'. Even though the hope for recovery is unrealistic for individuals with MND, an existential hope is relevant and maybe suggested (Soundy *et al.*, 2010).

Acceptance of changes, perception of circumstances, and the sense of control have all been observed to be influential in how people adapt to the changes following illness. Some take a passive form of coping strategy while others take an active form, depending on individuals' understanding of the situation. Also, it should be remembered that the coping style varies over time thus there also exists an internal dynamic. In addition it appears some forms of coping strategies are superior to others in their positive effect in terms of empowerment.

2.4.3 Decision making

When an individual becomes ill, it is likely that they need to make a decision regarding preference of care, including life sustaining treatment. Gauthier and Swigart (2003) observed the decision making in terminally ill patients (i.e. 9 patients with cancer and 1 with congestive heart failure) and found three determinants in the decision making process: *realisation of terminality*, *accommodating living*, and *engagement with uncertainty*. The first factor refers to the degree of awareness of mortality which involves reflection of physical ability and admittance of the changes. The second involves the realisation of the needs and adaptation to the changes. The last concept involves preparation for the unknown future with hope, preparation and anticipation. These three concepts were found to interact with each other and work as assessment criteria to understand where individuals stand in the decision making setting. In addition, this model appears to fit in with the previous reports.

For example, Reid *et al.* (2008) found that cancer patients viewed opioid treatment as the last straw and were resistant to have it until the symptoms became too severe to endure. This attitude towards opioids may be interpreted as a wrestle between the acceptance of death and physical deterioration (*realisation of terminality*): an attempt to deny mortality by not taking opioid which is identified as a manifestation of the terminal phase. This denial of the reality was observed to negatively affect decision-making by the dismissing of treatments (Johnson and Nelson, 2008). An impact of *accommodating living* can be perceived when patients express their fear of becoming a burden to others therefore welcoming death, sometimes even in the form of euthanasia (Chapple *et al.*, 2006; Johnson and Nelson, 2008): resigning from life instead of adapting to changes. It may then be further argued that the process of *accommodating living* includes adaptation of others, or perceived capability of another's adaptation. Lastly, the finding of the importance of the purpose in life as a motivation for life (Chapple *et al.*, 2006) can be explained by interaction of all three concepts. It can be argued that the future without a particular aim, or simply a lack of hope for the future in the face of awareness of physical changes, is evaluated as pointless. Such an attitude towards the future is presumably affected by their reluctance to adapt to changes. Even though these arguments support the importance of awareness, an awareness of the condition in MND may be difficult to some extent because of its difficult deliverance of accurate diagnosis and therefore prognosis (Hughes *et al.*, 2005) which is likely to create a sense of uncertainty about the future, delaying acceptance and adaptation to the changes and thus affecting their decision making.

In addition to these criteria proposed by Gauthier and Swigart (2003), the sense of control and perceived quality of life have been recognised to be other influential factors in how people make their decision. Chapple *et al.* (2006) argue that individuals may choose to actively welcome euthanasia as a way of controlling their lives, while losing the control over their body, and the right to make such a decision is seen as dignity. In terms of quality of life, although without consensus of its format, the previous studies seem to agree on the important role of intellectual function as one determination of quality of life (Chapple *et al.*, 2006; Johnson and Nelson, 2008; Lipsman *et al.*, 2007). For instance, undamaged cognitive function was observed to be valued more than prolongation of life (Johnson and Nelson, 2008; Lipsman *et al.*,

2007) and impaired cognitive function was the popular reason for a withdrawal from additional treatments in purpose of shortening lives (Lipsman *et al.*, 2007).

Hence, applying these findings of attitude towards treatments with terminally ill patients, it can be proposed that the decision regarding NIV use among MND individuals is likely to be dependent on their perception and evaluation of worthwhile-ness of their existence while there is also a consideration of the physical deterioration and its psychological consequences. It is postulated that the decision making process is a complex procedure involving individuals' evaluation of their physical condition, acceptance and adaptation to the changes, and their sense of control and quality of life.

2.4.4 Perceptions of NIV

There have been several studies conducted to explore the experience of NIV and these studies generally agree that there is both a burden and a relief associated with the use of NIV. These experiences of NIV then influence decision making regarding NIV use, and as may be expected, this process involves inner complexities just like it does with any other treatment decision-making as discussed.

Some of the reported negative experiences of NIV are the feeling of: being in a vacuum cleaner bag, being exposed to air pollution, and following the rhythm of NIV rather than the machine following the individual's breathing pattern (Lindahl *et al.*, 2005). Among the negative aspects of NIV, one prominent feature is recognised to be the mask (Lindahl *et al.*, 2003; Torheim and Gjengedal, 2009). It has been expressed that the mask sometimes intensifies anxiety by giving the sense of being trapped in it. This sensation negatively affects breathing which in turn causes the sense of losing control over the situation, inducing panic and irrational behaviour (Torheim and Gjengedal, 2009). In addition, the foreign nature of the mask, which creates a sense of otherness, was mentioned (Lindahl *et al.*, 2003; Torheim and Gjengedal, 2009), indicating the escalated threat to their identity initially generated as a result of the illness. Generally, however, it is perceived that the burden of NIV is primarily a result of the psychological disturbance generated by the implications of their need for a breathing assistance device and the fear of being dependent on it: existential and independence threats (Lemoignan and Ells, 2010; Lindahl *et al.*, 2005; Lindahl *et al.*, 2006).

With regard to the decision making of NIV use, some factors have been found to be influential and they suggest the importance of individuals' perception and

acceptance of NIV, and the belief in their need. With regard to perception, NIV was seen as a way to relieve symptoms, yet with this there was a concern also noted regarding the possibility of it triggering further deterioration. (Lemoignan and Ells, 2010). Also, studies show that adaptation to and acceptance of NIV is crucial; that this is a gradual process and this acceptance needs to be confirmed by the evidence of effectiveness (Lemoignan and Ells, 2010; Torheim and Gjengedal, 2009). Although individuals may need affirmation from healthcare professionals that NIV is necessary (Torheim and Gjengedal, 2009), or they may seek an opinion from significant others as their presence is essential in the patient's remaining time (Lemoignan and Ells, 2010), reflecting the significance of the social interaction. However it is ultimately the patients who evaluate if the burden associated with NIV outweighs the relief it may offer. Hence, the importance of the sense of control in decision making, discussed in the previous paragraph, is also apparent in relation to NIV (Lemoignan and Ells, 2010; Torheim and Gjengedal, 2009): an assessment of the need to use NIV and a subsequent act of decision as a way of controlling the situation.

Issues relating to the sense of control, identity, mortality and independence have been identified to be induced by the experience of NIV. Therefore, it may be argued that the experience of NIV is an extension of the experience of the illness, reflecting the individual's reaction to the changes. The decision of whether to use NIV seems to be based on these experiences and an evaluation of their life with NIV.

2.5 Summary

As discussed, illness causes dramatic changes not only physically, but also psychologically. It was observed that the loss of independence and the loss of control over the body following the illness affect the sense of self and self-esteem. Self-esteem was also perceived to be influenced by self-expectation in the context of social interaction. These changes are perceived differently by each individual and their understanding of the situation, sense of control, and the degree of acceptance of the changes have been observed to determine how people react and cope with the situation. The adaptation style is in turn found to influence decision-making, including the decision of whether to proceed with treatment. It has been reported that the decision is made following an evaluation of the situation and perceived value of their life. These factors relating to decision-making have also been recognised to be

pertinent in the case of NIV use. It may also be argued that some reported experiences of NIV among MND patients are a manifestation of people's reaction to the illness itself because of the implication of use of the machine and what it manifests, which is the fatality of the illness. The previous studies highlight the importance of understanding each individual's perception of their illness and how they are adapting to their illness in order to understand the reason for withdrawal from NIV treatment. It was proposed, then, that an in-depth interview with people who have refused NIV treatment for MND would help me to understand and elucidate where they stand and what influences their decisions.

CHAPTER 3

Research Design: Methodology and Methods

3.1 Introduction

This chapter deals with the epistemology of the study and the particular method chosen for the study, reflecting my philosophical position. Theoretical perspectives together with the ontology underlying the methodology are also discussed here.

3.2 Philosophical underpinnings of the study

The worldview, or paradigm, is a viewpoint by which actions are determined (Guba, 1990). In other words, the worldview directs researchers in their strategy (i.e. inductive/deductive), design of the study (i.e. qualitative or quantitative), and methods employed for research (e.g. ethnography, experimental research or phenomenological research). Among major worldviews such as postpositivism and pragmatism, the research presented here employs a constructivist worldview. Constructivism holds an assumption that people attempt to make sense of their world as they experience their world (Creswell, 2009). Furthermore, Creswell (2009) argues that this ‘subjective meaning’ of the experience varies between individuals and is also constructed by historical and social factors. Therefore, inquirers seek to understand the subjective meaning of the experience which is interwoven with the context of individuals. As is apparent then, the nature of constructivism also includes the worldview of interpretivism (Creswell and Clark, 2007). Interpretivism seeks to capture the meaning of concepts which are shared, either consciously or unconsciously, by people in a particular culture or time to explain their belief or actions (Lin, 1998). The term ‘verstehen’ is used to describe the reflexive observation of interpretivism (Scott, 2003). Scott (2002) explains the term by using the example of a person being in a foreign country and coming across a native joke. The person may not understand the joke fully, yet enough to understand why the native people find it funny.

This constructivism-interpretivism shapes the approach I took to understand the individuality of the experience of participants. Theory was generated inductively so that the theory which came out of the data was not a justification of my

preconception, but it was instead intended to reflect participants' experiences interpreted by my understanding of their world. In order to achieve this, IPA was employed where phenomenological and hermeneutic perspectives were maintained. The characteristic of this particular method harmonises with my worldview. In order to be faithful to this approach, then, my task was to 'bracket off' my preconception that NIV is a beneficial treatment, pursuing an understanding of the participants' experiences from their accounts. Even though total bracketing off is not possible as discussed in Chapter 1, an attempt to make known my position and the thread of my interpretation was made in the hope that this would help readers to assess my interpretation and subsequently the reported accounts of the participants.

3.3 Methodology and philosophical underpinnings

3.3.1 Introduction

Smith and his colleagues argue (2009) that IPA embraces three philosophical perspectives which are phenomenology, hermeneutics and idiography. The idea of phenomenology is derived from the argument that it is important to understand the essence of phenomena by going back to the subjects themselves. An interpretation is also crucial in IPA, because of the process involved in understanding the phenomena which are experienced by others. The last concept, 'ideography' is concerned with individuality, uniqueness, and real experience of particularity, while nomothetic is concerned with generality and invariability. In the next paragraphs, contributions of each perspective to IPA are discussed and these components are then related to my research question.

3.3.2 Interpretative phenomenological analysis (IPA)

The approaches of IPA are constructed using phenomenology, hermeneutics and idiography – the readers are advised to read *Interpretative Phenomenological Analysis: Theory, Method and Research* written by Smith *et al.* (2009) for the full explanation of IPA. IPA is interested in understanding human experience, which is studied rigorously via individual cases.

For IPA, phenomenology is concerned with the lived experience of the individual and it is distinct from a philosophical explanation of it, yet the contribution of philosophy to provide the description of the formats of phenomenology should be

acknowledged. The different theoretical accounts of phenomenology are seen to formulate the holistic account of phenomenology in IPA rather than any particular one serving as the core concept of it (Smith *et al.*, 2009). The claim of going back to the thing itself made by Husserl (1927) is understood as the call for going back to the experience of the individual (cited by Smith *et al.*, 2009): an experience of something of significance to the person and their attempt to make sense of the experience. IPA attempts to understand the lived experience and its meaning to the individual who is the holder of the experience. By understating the meaning 'impressed' by the individual, it may be possible that the existential aspect of psychology is discovered, as it reflects our essence in our entity and this idea is undoubtedly influenced by Heidegger (1962).

In order to understand the phenomena, IPA claims that an interpretation, or hermeneutics, of the individual accounts is crucial. This interpretation is not only carried out by researchers/interpreters, but also by participants themselves when they attempt to make sense of their experience, thus it is a dual interpretation. This dual interpretation or 'double hermeneutic', is a process of researcher/interpreters trying to make sense of both the individuals and their experience through their understanding and explanation of the experience. In addition, Smith *et al.* (2009) argues that IPA involves two levels of hermeneutics: hermeneutics of empathy and questioning. The former indicates its interest in understating subjective experience of the phenomena, that is to say, being in their shoes, whereas the latter implies its interest is in analytic examination of the experience. Although the hermeneutics of questioning provide different degrees of interpretation, its interpretation must always be generated from an interpretation of the account, therefore reflective practice is emphasised. Smith *et al.*, (2009) describe this close relationship between phenomenology and hermeneutics to be the crucial role in IPA: 'without phenomenology, there would be nothing to interpret; without the hermeneutics, the phenomenon would not be seen'.

An idiographic approach is highly valued in IPA for its accessing of details and sensitivity to the lived experience of particular phenomena which is perceived to be significant to individuals. Moreover, this commitment to idiography with detailed analysis has been identified as the way to provide an understanding of complex human psychology (Smith *et al.*, 2009) by providing systematic and detailed accounts. Three steps are involved in idiographic analysis. Researchers first conduct a close investigation into individual cases, which are later carefully compared with each other

for differences and similarities. In the last stage, the trends of meaning of the particular experience are identified. In this respect, it has been argued that in a good piece of IPA, accounts should provide readers with the variation of accounts within the general themes detected.

Hence, IPA is concerned with an understanding of lived experience of individuals who present their experience for interpretation. Together with gradual realisation of preconception of the phenomena, interpreters rigorously examine individual cases which subsequently provide a set of general themes, yet with variation and the uniqueness of each case. Also, the theory underlying IPA indicates that there is a universally shared human experience and this may be accessed through an investigation into a particular lived experience in a particular context.

3.3.3 An application to the current study

As discussed in the previous chapter, it was believed that an individual's perception, acceptance, and understanding of situations affect people's decision making. Therefore, it was proposed that an understanding of the experience of NIV would reflect the underlying reasons for NIV withdrawal.

In the current study, it was believed to be essential to engage with a phenomenological approach by going back to the participants themselves who actually experienced the events of being ill and being offered NIV. These experiences occurred in the context of interpersonal settings, where the presence of others would generate, or manifest, the individual's perception of the phenomena. Therefore, Husserl's (1927) argument of going back to 'the things themselves' (cited by Smith *et al.*, 2009) was valued as well as the importance of interaction with others claimed by Sartre (1948). Also the participant's account was thought to reflect the unique perception generated from their interaction with the world, reflecting the claim made by Merleau-Ponty (1962).

In consideration of Merleau-Ponty's (1962) argument that our experience only belongs to the person thus total comprehension is not achievable, it was assumed that total understanding of the experience of the participants was unlikely. In addition, the participants' accounts were expected in a measure to be incomprehensive, as Heidegger (1962) argues that people have the control of things they allow to be seen. However, I considered other claims made by Heidegger (1962) to also be important: the hidden account is fundamentally related to the revealed whereby the original

experience may be accessed. Therefore, an understanding of the experience based on the shared accounts, as well as what is not shared, by the participants was thought to provide an interpretation which was close to the original. The hermeneutic circle part-whole and single-sum were also practiced for diverse interpretations. In addition, a hermeneutic of a questioning approach was undertaken in order to gain different levels of interpretation. The cautions from these scholars with regard to the former preconception were noted and an effort to become aware of them and consequently bracket them out was made as they could bias the interpretations.

Based on the concerns relating to idiography, the findings of each individual case were reviewed and common factors were identified, while every effort was made to preserve idiographic uniqueness. Hence, this study aimed to understand the potential reason for the decision in each case, while attempting to identify the shared views among the participants, which may also reflect the science of human being.

3.4 Summary

In this chapter, the philosophical underpinning of the research, by which the theoretical approaches of the study were determined, was discussed. Now, the actual procedure of recruitment and data analysis will be reviewed.

CHAPTER 4

Data Collection and Analysis

4.1 Introduction

The main study employed both qualitative and quantitative methods. With regard to the qualitative phase, semi-structured interviews were conducted and the data was analysed by using IPA. In terms of the quantitative phase, various scales were selected and questionnaires were designed separately for patients and their caregivers. The scales used for patients were ALS Assessment Questionnaire-40 (Jenkinson *et al.*, 1999), ALS-Functional Rating Scale (Cedarbaum *et al.*, 1999), MND Dyspnoea Rating Scale (Dougan *et al.*, 2000), Beck Depression Inventory (Beck *et al.*, 1996), Beck Hopelessness Scale (Beck *et al.*, 1974), hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983), and Epworth Sleepiness Scale (Johns, 1991). The questionnaire for caregivers, both lay and professional, included: NEO Personality Inventory (assessed only at the initial session) (Costa and McCrae, 1985), Dispositional Resilience Scale (only assessed at the initial session) (Bartone *et al.*, 1989), Caregiving Distress Scale (Cousins *et al.*, 2002), Sense of Competence Questionnaire (Vernooij-Dassen *et al.*, 1996), and the short version of Zarit Burden Interview (Bédard *et al.*, 2001). Furthermore, records of patients respiratory functioning were assessed by using spirometry, mouth pressure test, sniff nasal pressure, and nocturnal pulse oximeter, which is to measure arterial blood gas level. Arterial blood gases were also recorded at the baseline and interaction data with NIV was also obtained for those who had been established with NIV.

4.2 Participants

A total of 35 patients with their lay caregivers and 23 professional carers were recruited for the main study by employing purposive sampling. Out of these patients, 17 patients went on to NIV treatment and 5 patients deceased while they were being assessed for their need of NIV. At the time of writing up this thesis, two patients were still undergoing monitoring and had not been offered NIV treatment. The remaining 11 patients had been offered the treatment but had withdrawn from or declined it. The recruitment was carried out by myself and another research assistant.

All the patients and their lay caregivers were asked about their interest in participating in the study once they were referred to UHA from WCNN for respiratory assessment and consideration of NIV establishment. The study was first mentioned to the patients by neurologist or respiratory physicians and followed up by the research assistants with more information for the patients. Consent (see Appendix 2) was obtained once patients agreed to take part. With regards to the recruitment of professional carers, only carers actually on treatment with NIV were recruited. Some of the names of professional carers were given by patients, while some others were identified with the help of the MND Association, which supports MND patients and their caregivers. The identified professional carers were contacted by phone call by the research assistants and asked about their interest in participation. No different procedure was used in the recruitment for the 11 chosen participants included in this study.

This thesis presents the 11 patients who decided that NIV was not for them thus this group was purposively chosen from the bigger cohort. The purposive sampling of the 11 patients was to meet the aim of the study which was to understand the lived experience of individuals in the particular situation: going through a decision making stage of NIV and subsequently withdrawal from NIV. The criteria of the sampling were that they had been diagnosed with MND and withdrawn or declined from NIV treatment when offered. Smith *et al.* (2009) argue the importance of homogeneity in IPA for researchers to explore psychological divergence among participants. They argue that a homogeneous sample reduces the number of possible reasons for the divergence; such as divergence caused by social background (Smith *et al.*, 2009). Although it may be argued, then, that the sample of the current study seems not to be homogeneous, for example, in their age (ranging from 40 to 79) or their stage of the illness (see Table 4), it may be noted that the whole population of this particular group is small, thus selective sampling would only restrict the exploration of their experience of the phenomenon; that is, the decision making of NIV within the context of MND. This view of homogeneity in a sample of small populations is supported by Smith *et al.* (2009) and it was, therefore, considered that the diagnosis and their declining of or withdrawing from NIV were the most important factors for the sampling of the current study. Due to the time frame, only the accounts from patients were examined for the purpose of this thesis. Nonetheless, it was presumed that any significant influence of caregivers would be reflected in their accounts.

Because of the different central focus of the main study and the difficult nature of distinguishing the potential sample in this uncommon neurological disease, further recruitment did not take place. Nevertheless, the aim of IPA is to recognise general experience of the particular and this type of study often includes only a small group (Brocki and Wearden, 2006). Accordingly this study also follows the norm.

Once patients showed signs of hypoventilation, their condition and the reasons for their need of NIV were explained to them by respiratory doctors at the NIV clinic. Generally, patients were then introduced to a physiotherapist who physically showed them different types of mask available to use NIV. Any question raised by patients during clinic was answered by either doctors or physiotherapists and patients were provided with their contact numbers for further queries. Out of 11 patients who were approached by the researcher and agreed to take part in the study, one patient was excluded from the analysis as the interview did not include underlying reasons for the withdrawal. The field note just after the interview reads:

The patient and her husband made it very clear at the beginning that they wouldn't want to talk about the illness. But apart from that they were happy to take part in the study. The carer seemed to be very careful with how the patient feels and he said he would not want to discuss anything to upset his wife, which was understandable. Because of that, it was difficult to ask them about diagnosis and information seeking. It turned out that her diagnosis was this January so I could see that she is deteriorating quite rapidly [9 months after the diagnosis]. The patient did not answer many questions in the questionnaire either and they were on hopelessness and emotional feeling (possibly burden as well). They only expressed their positive expectation for a NIV trial.

Among the remaining 10 participants (female=2) 7 were agreeable to a trial of ventilation when offered and tried NIV at least once before their withdrawal, while three participants declined without undergoing the trial. Of those who tried NIV, all decided that NIV was not for them fairly quickly, except Henry who used NIV for a period of just over two months before his withdrawal. Table 3 contains relevant factors in relation to the participants. 'Months after diagnosis' in the table is the period since diagnosis to the time of interview, while 'time before trial' indicates the

period after their diagnosis and during which patients were being assessed by respiratory clinicians for NIV need. Their names are all anonymous for the purpose of confidentiality.

Table 4 provides data on the disability stage of each patient measured by the respiratory functioning test (FEV1 and FVC) and nocturnal pulse oximeter. The relationship with their main lay carer is also presented together in the table with scores on hospital anxiety and depression Scale (HADS) (Zigmond and Snaith, 1983), 40-item amyotrophic lateral sclerosis assessment questionnaire (ALASQ-40) (Jenkinson *et al.*, 1999), and amyotrophic lateral sclerosis functional rating scale (ALSFRS) (Cedarbaum *et al.*, 1999) – these quantitative data were gathered for the main study. Demographic data such as their previous occupation or year spent in education were not included as criterion in the main study and are thus not accessible.

4.3 Data collection

Semi-structured interviews were carried out. Interviews were conducted at the participant's home or hospital, depending on their preference. The length of interviews varied between 16 minutes and 1 hour, depending on the condition of the participants; sensible decisions were required to judge the tiredness of the participants and unnecessarily lengthy interviews were avoided. Their preference of the presence of their caregiver during their interview was also respected, although it was our preference to interview the person alone. Most patients were interviewed separately from their caregiver apart from Simon and Ted. Initially, visits were to be made every three months to observe attitude change over time, yet as seen in Table 3, many had only one or two visits. This was due to the mortality of the illness, as mentioned in Chapter 1, and also the timing of the referral to UHA. The referral was based on the concern they were developing or at risk of respiratory symptoms; but also because of the plan to follow a cohort of people with MND prospectively and longitudinally and (as seen in Table 3) most patients were not referred to UHA at the initial phase of the illness, reducing the opportunity for the number of visits. In addition, the visits were sometimes postponed if patients had been hospitalised due to a chest infection or some other reason, or if patients requested rearrangement because of their poor

Table 3: Factors Related to the Participants

Anonymised name	Age	Date of diagnosis	Time before trial (month)	NIV trial	Total number of interviews	Interviews Used for analysis**	Time between the diagnosis and the first interview (month)	Months after diagnosis***	Was the interview conducted by the other researcher?
Catherine*	64	31/03/08	14	Yes	1	1 (pre trial)	12	12	Yes
Henry	77	01/10/09	1	Yes	2	1 (post trial)	1	3	No
Ian	71	18/06/07	27	Yes	8	2 (1pre and 1post trial)	11	25, 28	Yes - pre trial
John*	58	20/02/06	-	No	2	2 (pre trial)	24	24, 28	Yes
Matthew	79	05/10/07	17	Yes	3	1 (1post trial)	9	17	Yes
Peter*	72	19/06/06	-	No	1	1 (pre trial)	20	20	Yes
Rachel	40	27/11/09	1	Yes	2	1 (post trial)	<1	4	No
Simon*	71	19/05/08	16	Yes	2	2 (pre trial)	10	10, 15	Yes - one pre-trial
Ted	71	12/05/00	118	Yes	3	1 (post trial)	113	120	No
Timothy*	76	18/06/07	-	No	1	1 (pre trial)	7	7	Yes

*post-interview not available

** see 4.4 Data Analysis for the choice of interviews

*** at the time of interview

Table 4: Relation with Their Carer and Other Relevant Factors at the Time of NIV Referral

Anonymised Name	Relation of Lay Carer to the patient	Onset	Bulbar at the time of trial	HADS-A	HADS-D	ALSAQ-40 Emotion	ALSAFRS Total	FEV1 (predicted%)	FVC (predicted%)	FEV1/FVC %	Oximetry (>90%)
Catherine	Offspring	Limb	Yes	4	6	27	24	0.46 (33%)	0.48 (28%)	95.8 (80.9)	3:06 hrs
Henry	Offspring	Limb	Yes	3	10	14	30	1.6 (63%)	2.37 (69%)	67.5 (74.3)	0:43 hrs
Ian	Partner/spouse	Limb	No	3	3	18	40	1.24 (39%)	2.21 (54%)	56.1 (77.2)	2:00 hrs
John	Partner/spouse	Bulbar	Yes	12	9	19	18	N/A	N/A	N/A	6:01 hrs
Matthew	Partner/spouse	Bulbar	Yes	5	9	17	24	N/A	N/A	N/A	9:37 hrs
Peter	Partner/spouse	Limb	Yes	4	11	25	21	0.98 (40%)	1.2 (38%)	81.7 (77.2)	N/A
Rachel	Partner/spouse	Limb	No	2	8	12	26	1.81 (58%)	2.17 (62%)	83.4 (88.6)	1:30 hrs
Simon	Partner/spouse	Bulbar	Yes	5	4	21	33	2.6 (97%)	3.29 (94%)	79 (81.5)	0:14 hrs
Ted	Partner/spouse	Limb	No	2	7	4	25	4.08 (120%)	4.82 (111%)	84.6 (78.2)	0:02 hrs
Timothy	Partner/spouse	Limb	Yes	13	8	32	11	N/A	N/A	N/A	N/A

HADS-A: hospital anxiety scale, HADS-D: hospital depression scale, ALSAQ-40 Emotion: Sub-total of emotional scale from ALS Assessment Questionnaire-40, ALSFRS: ALS-functional rating scale, FEV1, FVC and FEV1/FVC %: spirometry, Oximetry: nocturnal pulse oximeter

condition on the scheduled day. Some of the interviews analysed and presented in this thesis were conducted by the other researcher, which is indicated in Table 3.

All ten participants had a pre-trial interview, whereas post-trial interviews were only available for 5 patients since three declined the NIV trial or they passed away ($n=2$) before they had a post-trial interview. In post-trial interviews, possible reasons for withdrawal from the NIV were sought by asking about their experience of NIV. An interview schedule (Appendix 4) for the main study had already been established by 1 neurologist, 2 respiratory physicians and 1 psychologist prior to my involvement and this was used as a prompt. A few examples of the questions from the list are: “What were your thoughts when you were told that you had MND?” as a question regarding their diagnosis, and “What did you think when you were shown and started on the ventilator?” with regard to their experience with NIV. All the participants were encouraged to speak freely about their concerns and thoughts regardless of content or any desire to be polite. Field notes were also entered from each interview, noting unrecorded information such as conversations before or after the interview. This approach of recording field notes is highly recognised in ethnography, where field notes may be the sole accessible data (Palmer, 2010). In the same aspect, field notes were used in the current research as the only data for John, who declined the formal interview, yet remained keen to participate in the study, and only as supplementary data for the other participants, including the patient who was excluded from the analysis. Two ways of taking notes were employed: observational notes and theoretical notes (Palmer, 2010). The former records descriptive and factual events, while the latter includes the researcher’s thoughts and impressions. Although both approaches were used, it was mainly the observational notes which were used for the analysis of John’s interviews in consideration of phenomenology and hermeneutics of IPA. The theoretical notes were used to become aware of my own thoughts, generated by the interviews, which can consequently be bracketed off. Therefore, the use of field notes was perceived to provide data which was otherwise difficult to obtain and also to enhance the process of IPA. Although it may be argued that the analyses of John’s interviews should be excluded, the limited number of people who fit into this sample category should be recalled; that is, individuals who experience this phenomenon of being diagnosed with MND and who decline or withdraw from NIV treatment. Therefore, it was essential to hear the views of this

group of people on NIV treatment, including John and those who have communication difficulties which are now discussed.

Interviews were normally conducted verbally. However, some strategies were employed to mitigate communication difficulties with patients who had dysarthria (unclear speech articulation). Sometimes this simply involved allowing them more time to deliver speech and extra careful listening while they spoke. Confirmation of what they had said was sometimes sought to ensure that they were correctly understood. Hand writing was also employed if verbal communication was unavailable or too much of a struggle for the patient, yet even hand writing was found to be unobtainable with Peter and Timothy, whose limb muscles had deteriorated and who were unable to write. In such cases, closed questioning and simple questions were employed so that only gestures or short answers were required. An example of this technique is extracted from the interview with Timothy (the extract is later used in the analysis):

I: Did you consider what benefits the ventilator might give you when you made the decision?

P: [Nods head] Spells: M-A

I: M - The mask?

P:[Nods head]

I: You just thought about the mask?

P: [Nods head]

I: And was it specifically the claustrophobia with the mask?

P:[Nods head]

I: That was the only thing that really mattered to you at that time?

P: [Nods head]

*I=interviewer, P=patient

Although it might be argued that questions in such a form would be leading and therefore could lead to misunderstanding or misleading, each point was rechecked and confirmed with the patients. The need for communication alternatives were also expressed and justified by Philpin *et al.* (2005) in interviewing and attempting to understand individuals with speech difficulty. This approach in IPA, however, demands more justification in consideration of its philosophical underpinnings:

phenomenology, hermeneutics and idiography. While closed questions still enable researchers to engage with phenomenology and idiography, they appear to provide little space for hermeneutics. Nevertheless, it may be argued that rechecking and gaining confirmation from the individuals are seen to stand in the realm of double hermeneutics. For instance, from the extract above, it may be argued that the term “claustrophobia” was introduced by the interviewer and thus possibly leading, yet the participant’s agreement indicates that the interviewer’s interpretation is accurate, which was that the mask had negative associations. Like the use of field notes, this approach was seen to be vital in order to include as many individuals as possible who were experiencing the phenomenon. The patients who needed these communication strategies were Peter, Simon and Timothy.

All of the interviews were audio recorded except interviews with John who declined to have formal interviews, so only field notes were available for him. These field notes were entered by another researcher who conducted the interviews with the patient. Therefore, a particularly stringent approach to interpretation of the notes was employed and any accounts in the notes that it was difficult to be categorical about were omitted from the analysis. An example of such issues with regard to notes being discounted is seen in an extract from an interview with John. In this account, even though the notes observe John apparently avoiding thoughts of the future was recorded elsewhere and thus likely, the degree of reassurance needed is not clear. Therefore, a possible interpretation of John’s anxiety or pressure created by an interaction with researcher was not noted.

He indicated that he wasn’t thinking about the ventilator for now or the future – indeed he seemed to suggest that he didn’t really want to think about the future at all. He seemed upset at the subject and needed some reassurance that it was ok not to think about it if he didn’t want to and that he only had to talk about things if he wanted to.

Other interviews were rigorously transcribed verbatim. In terms of transcribing, a plausible issue, that of English being my second language, may be noted first. To overcome this issue, however, the accuracy of a group of transcripts was checked by a respiratory physician and having been thus validated the quality of other transcripts was accepted. Secondly, transcribing was particularly challenging with patients who

displayed dysarthria, requiring repeated checks for accuracy. In spite of this painstaking effort, some parts remained inaudible and were indicated in brackets. These communication difficulties need to be addressed and reflected in the consideration of its impact on the phenomenological approach: limited access to the experience of the person. Nevertheless, it was believed that each participant was able to share the underlying reason for the withdrawal, even from the accessible accounts or parts of accounts, sometimes indeed these were excessively well expressed.

4.4 Data Analysis

The decision as to which transcripts to use was based on the richness of the data, which was sometimes affected by participant's poor speech. The interviews just before or after the trial were usually used for the analysis (see Table 2 for transcripts used) which seemed to provide their views on NIV most relevantly and to reveal any plausible reasons for their decisions.

The data analysis began from the time of data collection where participants' accounts of the experience were listened to carefully in order to minimise my preconception and to understand their experience through their perceptions which were only directly available to me. Therefore, an aspect of the hermeneutics was sought during this phase of the study. During this stage of data collecting, it was also essential to build a good rapport with the participants so that they would feel comfortable to freely talk about their perceptions.

After the data collection, the steps for analysis introduced by Smith *et al.* (2009) were modelled. The first stage of analysis is concerned with the familiarisation with the data achieved by means of listening to and re-reading of the interviews so that the nuance of the accounts was not lost. This process was especially identified to be crucial with the data collected by another researcher, thus more repeated readings to become familiar with the data were involved with these transcripts. After the first stage, the right-hand margin of the transcript was used for detailed and comprehensive initial annotation. Initial notes were made for effective understanding by three different levels of analysis: descriptive, linguistic, and conceptual comments. The descriptive comments are the most basic level of understanding, recording descriptions of content and key words or phrases used by the individuals. These comments highlight the experience and the thoughts of participants. The linguistic

comments analyse the participants' linguistic usage. The focus here is phrasing, pause, repetition, fluency or metaphor used by individuals to describe their experience. The importance of linguistic articulation is in its bridging role between the descriptive and conceptual comments. The conceptual comments are the most interpretative procedure of the three. This process reflects IPA as phenomenological and hermeneutic analysis in that an inquirer moves away from apparent expression made by the participants and moves towards the overarching themes of the participants' accounts. This stage often involves questioning and raising tentative conclusions or themes which are refined through re-visiting the data and by reflective practice of a researcher's unique preconceptions. Smith *et al.* (2009) claims that a richer analysis is produced where there are many interrogative and abstract forms. However, it is nevertheless essential that the interpretation is founded on ideas emerging from the transcripts.

The next stage of the analysis is a development of emergent themes. The emergent themes are based on the initial comments and the transcript; the initial source for the themes is the detailed comments rather than the transcript itself which is used to check the consistency of the themes. This stage is more analytic compared to the previous stages where the researcher is tasked with reducing the comments to themes while retaining the complexity of a meaningful interrelation of the comments. The themes are 'usually expressed as phrases which speak to the psychological essence of the piece and contain enough particularity to be grounded and enough abstraction to be conceptual' (Smith *et al.*, 2009). Thus, the characteristics of phenomenology and the hermeneutic circles are respected. Themes are to be congruent with the account, yet they also capture what the participant does while they describe their experience and are formed by the researcher's interpretation of this dynamic process. Therefore sound themes should contain both the participant's and the interpreter's understandings of the phenomena.

The fourth stage of the analysis aims to organise the emergent themes. In this stage, some themes were clustered under more overarching themes while some were discarded, according to their relevance to the research question and to their significance in the whole-part hermeneutic circle. In order to capture the whole picture, the list of themes was printed out. The themes were then cut up individually, so that how they related to each other could be explored. Among some suggested models, a mixture of 'abstraction' and 'subsumption' were used to identify patterns

within the themes, which were then put under more general themes: supreme-ordinate themes. The ‘abstraction’ form identifies groups of themes by clustering the themes according to consequences of events described in the account, such as ‘reaction to the diagnosis’. The grouping for ‘subsumption’ is similar to that of ‘abstraction’, but its focus is on psychological flow (e.g. sustaining previous identity). Generally, ‘abstraction’ was chiefly used for more descriptive transcripts while ‘subsumption’ appeared to be effective for transcripts which contained more abstract and reflective accounts. Once super-ordinate themes were identified, a table was created with their sub themes. The same steps were taken to analyse the rest of the transcripts. Although it was inevitable that the previous analysis influenced my perception when I moved onto the next transcript, the principle of idiography was applied and each transcript was analysed systematically.

Once all transcripts were individually analysed, the tables of the themes were brought together to find the pattern across the cases. This was a creative process where higher concepts were identified, however, allowing idiographic colour to radiate their unique experiences. For instance, one of the sub themes for “not needing NIV” was identified to be “no significant changes” in their breathing or sleeping pattern thus they did not need NIV, yet the reasons for not having significant changes were observed to differ between the patients: different causation other than MND for changes, luck for having apparent changes, evidence to support no change, and a solution for the changes. A table was created for each concept with the extracts from the transcripts which reflect the subthemes. The number for the lines suggested by Smith *et al.* (2009) was omitted as it was easy to allocate the extract using the Microsoft Word programme. Because of the specific aim of this study, which was to find out the underlying reasons for withdrawing or declining NIV, all identified reasons were included, yet all the concepts were supported by more than 1 participant.

4.5 Validity of the analysis

The validity of analysis is dependent on its faithfulness to the original accounts, which is apparent in the description and procedure for analysis as described above (Osborn and Smith, 1998; Smith *et al.*, 2009). As a part of the examination of the faithfulness of my analysis, triangulation was sought with one of my supervisors regarding one interpretation whereby some modifications were suggested. For instance, it came to

my notice that I had a tendency to understand participants' conditions from a medical perspective rather than from the participants' point of views. Therefore, my bias that healthcare professionals are generally accurate in their judgement was addressed and an effort was made to bracket it out. The rest of the data were analysed according to the suggestions. The finalised table of the main concepts throughout all the data were also evaluated with the supervisor. Transparency of the analysis was sought by making the process of the analysis accessible to the reader so that the credibility of my interpretation may be examined. Field notes were also kept for the purpose of self-reflection, to examine my perception of particular phenomena (Brocki and Wearden, 2006). It should be understood that the interpretation presented here is not the sole interpretation of the accounts, but one of multiple potentially (Smith and Osborn, 2003).

4.6 Ethical concerns

All the processes regarding the research ethics had been made prior to my involvement in the study. The research applications were first made to UHA, WCNN, North East Wales NHD Trust, and University Hospital of North Staffordshire NHS Trust and were given permission to conduct the study. The application for ethical review was sent to the Liverpool Local Research Ethics Committee and was approved on the 20th December, 2007: reference number 07/H1002/82.

All of the participants were provided with an information sheet (Appendix 3) in which their confidentiality and anonymity were guaranteed. Their right to decline or withdraw from the study was explained and that there would be no negative effect on their treatment as a consequence of their decision was emphasised. Similarly, the participants were assured that they did not need to answer any of the questions either in questionnaires or interviews if they wished not to. They were also encouraged to speak to me, or co-researchers for the main research project, to address any specific issue generated as a result of the study. The numbers for National Health Service complaints mechanism and Patient Advice and Liaison Service at the WCNN were also provided in case they preferred to report their concerns.

There is a view held that it is not appropriate to recruit terminally ill patients in a study (de Raeve, 1994). However, in their qualitative study in a palliative care setting to investigate patients' perception on study participation, Gysels *et al.* (2008)

argue that patients were able to make up their own mind regarding their involvement in a study. They further report that those who agreed to participate in the study did so to make their voice heard or simply to have some company. I agree with their arguments that potential participants are all capable individual decision-makers in their own right and should be given the opportunity to express themselves or have the advantage of being involved in the study. I also acknowledged their capability of to reconsider their continued involvement in the study: i.e. to withdraw. Indeed, two participants, Peter and John, reconsidered their participation and subsequently declined to continue in the study. The earlier data obtained from Peter and John were used for the analysis and presented in this thesis as the participants did not request the data to be removed.

CHAPTER 5
Findings

5.1 Introduction

The findings of the analysis are presented here. The steps of IPA described above were followed and each transcript was analysed one by one. After idiographic analyses, overarching themes between transcripts were identified and a table was made with these. Individual analyses (see Appendix 5) as well as the table for each theme with extracts are bound into Appendix 6. In this chapter, the summary of findings for each concept is first presented, reflecting the shared experiences of the participants who decided that NIV use was not for them. The summary is then followed by a detailed examination of how the concepts are reflected in individual account. In the extract, ‘I’ and ‘P’ represent sentences uttered by interviewer and patient, respectively. All of the names are anonymous and the brackets are used to supply the missing information.

5.2 Preservation of the self

A negative impact of the physical changes caused by MND on decision making was observed and analysed in this first concept that emerged from the interviews. The physical changes limit activity and disable participants, so preventing them from engaging in their previous activities. Because of what they could not do, they felt that their identity was challenged to their accepted identity and that they were left with a new inferior identity. The common feature of the new identity was an absence of independence. It was understood that the new, inferior identity was not fully accepted and prolongation of life with the new identity was not welcomed. The prominent concern for these participants appeared to be a preservation of the self, by which I mean autonomy, dignity and quality of life. For these patients (n=4), NIV was perceived to be a symbol of insignificant existence which takes away their lives and eventually makes them live longer than they wish without what they perceive to be dignity. This perception was also influenced by their recognition that breathing is an essential function for life. The use of NIV was observed to be in opposition to how they preferred to spend the last stage of their lives: live life without NIV which would

prevent them from having a real life. Because of their concern for self and the implications of breathing problems, NIV was not accepted.

Physical changes in MND were always mentioned by all of the participants as unavoidable phenomena, however the consequences of the changes were especially referred to by some participants:

And as well, she didn't shave me so I ain't had no shave now and I hate that. I've always had a shave every day of my life I have. I think that might be the worst thing about this motor neurones'. (Matthew, post trial)

When talking about his carer, Matthew disclosed his annoyance with the carer who did not practice the ritual of 'shaving' that he had always practiced. Although on the surface, this annoyance appears to be generated by simple neglect of one previous habitual activity, this was perceived to be critical for Matthew, 'the worst thing about this motor neurones', and it was understood that this was because of what the ritual manifested: his identity. In other words, the aggregation of his previous habits shaped what he was. Now, his impaired independence disables him to maintain his previous identity and his identity is injured by his carer. This notion of previous habits composing identity was common as Simon also discussed:

I always used to wear a shirt- had to, you know, had to be smart, take care, look good. Always used to wear a shirt every day and have a shave and now I can't. I have to wear tops without buttons and I hate that. It's not really me anymore because of what I can't do – the fiddly things like buttons. In business, it's important, you know, dress the part – not like this, I hate this now that I'm wearing. (Simon, pre trial)

Even though the previous habit was initially compulsory, as he stated he 'had to', wearing a shirt had become a part of his identity which was now damaged because of his physical deterioration. However, his fundamental identity appeared to be his status as a businessman rather than him simply wearing a shirt. The shirt was understood to be a 'part' of being a businessman, thus his previous habit of wearing a shirt was a crucial attachment to his identity. Despite the fact that Simon was not working in business any longer, he still identified himself as a businessman and his impairment

denied the identity. In consideration of this, it may be further argued that an identity is not determined by a social status as such, but by an individual's perception of themselves. Therefore, in the case of Simon and Matthew, their identity was closely associated with their independence to practice previous rituals and their inability to conduct the rituals consequently negated their identity. This struggle between their past identity and the new identity was a common observation among the participants, and the new identity was perceived to be unacceptable:

I don't want to just [long pause] fade away, just a helpless thing. That really is just the worst thing that could ever happen to me; because, well, it must be hard for you to see it now 'cause you never knew what I was really like, but it's not how I've lived my life, like this, and I'm just so sure that it's not how I want to go out either. I want this all really to be over as soon as it can be; I wouldn't want to live much longer, and certainly I wouldn't want people trying to keep me alive longer than was natural – longer than the disease wanted me alive. So, if there's no cure, I don't want to be messing with anything else, you know?
(Catherine, pre trial)

In this extract, Catherine refers to her current status as brought about by MND as the worst event, destroying her life by disabling her and making her 'an old lady sat in a chair dying'. Catherine seems to place her identity in her independence which has now been impaired, making her into a different person who is too distinct from her previous self to recognise. Moreover, this extract indicates that an impaired autonomy further questions her quality as a human being and her devastation over her current condition can be seen in her depersonalisation of herself as a 'helpless thing': a 'thing' which does not possess the faculties to be a human being. It can also be interpreted that the process of 'fading' of the muscle is also causing the 'fading' of her sense of existence as a human. It is apparent, therefore, that independence and autonomy are essential factors for Catherine in terms of her identity and furthermore for her to remain as a human being. Facing this threat, she stated no interest in 'messing with anything'. In consideration of the context, it was understood that she would not want to be 'messing with anything', such as treatment, to preserve her dignity or her sense of self. The concern for dignity was prominent in the group and it

was related both to the way of maintaining and ending their lives. Ian uses an example of another patient with MND to portray this point:

what's-his-name, um, [MND patient] well, but look at the state he's in. What kind of a life is that? I mean his brain is still alright; that's still alive, but that's all though. (Ian, pre trial)

Here, Ian refers to a person with MND whose mobility had been impaired and only cognitive function remained. By referring to this individual, Ian seems to be suggesting that the quality of being for him consists largely in mobility, but little in cognitive function. Furthermore, it may be interpreted that for Ian the mere functioning of the brain without any mobility does not count as a life as such, but just an existence. This argument points to the importance of perceived quality of life. Even though the definition varies between people, it was interpreted that a good quality of life involves mobility as far as Ian is concerned.

The image of lifeless existence with the illness, either with or without cognitive functioning, was also raised by other patients and NIV was perceived to be a symbol of such existence. For instance, Simon's concern was regarding the restriction on living as a result of NIV use:

I don't want to end up like one of those people who just lives hooked up to a machine. They're not really living, I wouldn't want it to be all of the time and not have any life. When I first heard it – that was what I thought. That was my first thought when I heard it. That's what I'm afraid of – if I start on that a little bit. [Long pause] I don't want that. You can't do anything. (Simon, pre trial)

His impression of NIV was that it presented an obstacle to having a life and he claims that life cannot be obtained while 'hooked up' to a machine. The imagery of being hooked up may be likened to that of an electronic device which needs constant charging: NIV will be his energy resource and he cannot live without it. The use of an illustration of being hooked up to NIV may be interpreted as his impression of the loss of independence or freedom to have life once he starts using NIV. Although he seemed to acknowledge that NIV is not for continuous use, he displayed his fear that to have NIV as a life sustainer would ultimately result in forfeiting a real sense of

living. Thus, his fear may be interpreted as a result of predicted antecedent loss of independence and control. This image of complete reliance on NIV was also captured by Catherine, referring to NIV as something which someone would rely on for ‘the rest of your days’. Furthermore, the image of NIV was strongly related to the end-of-life stage for Catherine, which was apparent in her account of one patient with MND she knew:

I remember his, um, he [MND patient] was really breathless almost all of the time in the end, towards the end, and fighting, you know, really fighting to breathe sometimes actually – hanging on to life really I suppose. You know, despite all how he was the rest of him. That surprised me actually. So, um, what I thought was that I didn’t want to end up like that gentleman in the home, fighting for breath and clinging on to life like that. He was in my mind a bit.
(Catherine, pre trial)

She expressed her surprise at the reaction of the MND patient who was desperate to live. In contrast to this patient, this account indicates her preference, of terminating her life, if she were in his condition. It can be understood from her words ‘despite all how he was the rest of him’ that the issue she is concerned about is the quality of being which is resonant in her previous extract. Also, by referring to him as ‘hanging on to’ and ‘clinging on to’ life, Catherine expresses the person’s lingering and holding on to the life, which for her had already been sentenced with a verdict of no real sense of life. For her, life is not worth fighting for when breathing is all that is left to her and in her view this is without autonomy or dignity. Indeed, it was verbalised by her elsewhere that ‘acceptability’ of her status and ‘dignity’ are important aspects in her dying process. Because of her witnessing the man at the end-of-life stage, the link between life and breathing had been identified. It was felt that NIV was negatively perceived by her: keeping her alive ‘more than the disease wanted’ her to live without quality of being.

The frustration over their new identity associated with their impaired independence, as well as the fear of becoming dependent on NIV, was explicitly displayed by participants. Their concerns were the maintenance of autonomy, dignity and quality of life rather than a prolongation of life. The issue of the sense of self was

most apparent in this concept, yet, as will be discussed, it was perceived that this aspect also reflects how other factors were experienced by participants.

5.3 Personal perception of intervention with NIV

Some of the common reasons (n=7) for withdrawal from NIV were the result of their perceptions of the effects of NIV and these were often found to be caused by an anxiety and a belief that there may be an adverse outcome of the use of NIV. Their experience of using NIV was perceived by them to result in worsening the condition, causing confusion and discomfort. This concept illustrates how individuals' negative experience or image of NIV can become a belief that NIV is a hostile machine thereby affecting their decision making. However, this reaction was also in effect understood as a result of their sense of the loss of autonomy with NIV.

Most participants expressed concern with some features of NIV, such as the mask. For Simon, however, a negative image relating to NIV features was addressed only briefly, indicating its subordinate negative aspect of NIV to him: 'Just [long] having it on my face. But maybe it won't be so bad' (Simon, pre trial). Likewise, Catherine briefly mentioned the preconception of the mask:

Oh it just seems a bit; well it's scary having something like that on your face I think. And I'd imagine it's quite claustrophobic as well; yeah, just having to wear that thing – doesn't sound very nice to me. (Catherine, pre trial)

Here, Catherine raises two aspects as possible reasons for not liking the sound of NIV: the appearance and claustrophobic nature of the mask. With regard to appearance, even though she made a reference to the mask as scary, from which her concern over possible alteration of her identity by a change in her appearance may be seen, her concern regarding the mask was understood to be more related to an issue with her identity in terms of her dependency. This presumption was based on the observation that the issue of appearance was only briefly mentioned here in contrast with the dominant topic of independence raised throughout the interview. Thus, her account of claustrophobia here can be understood as an indication of her issues over autonomy and sense of control. It is arguable that NIV does not sound nice to her as it

gives an impression of losing control due to the mask. Her concern over the mask was induced by her perception of the mask as manifesting her impaired independence.

While an adverse outcome of some features of NIV is not excessively verbalised by either Simon or Catherine, it was the main concern for some other patients. The quote from Timothy, who declined to have a trial, illustrates the significance of the mask:

I: Did you consider what benefits the ventilator might give you when you made the decision?

P: [Nods head] Spells: M-A

I: M - The mask?

P: [Nods head]

I: You just thought about the mask?

P: [Nods head]

I: And was it only the claustrophobia* that was a concern to you?

P: [Nods head]

I: That was the only thing that really mattered to you at that time?

P: [Nods head]

(Timothy, pre trial)

As is evident, the mask was the only concern for Timothy and he further indicated that there was nothing which could change his mind, demonstrating the great impact of this feature. However, it was not clear why Timothy was so clear about his dislike of the mask from the interview, presumably due to his limited verbal communication. The issue with claustrophobia was addressed by Ted:

P: It's just something I just.... it might be something I am frightened of. I don't know what it is – as though you trap something....

I: You trap something?

P: You know some people trap when they go into dark place or something like that people... what's they – claustrophobia – I just don't want it... I don't want it on me face anything on me face.

(Ted, post trial)

It appears that there is no clear explanation for claustrophobia but what is seen is a confused and emotional experience, which can be seen in his poor articulation and the further observation from his quote that he could not pin down the exact phenomena he was concerned about. His use of the metaphor of being trapped, illustrates the sense of insecurity and anxiety at not knowing the situation or the way out. Therefore, it may be interpreted that the mask is a threat to his security and its use seen as a 'frightening' experience. As a result, he simply states that he does not want it. This somewhat impulsive reaction towards the mask was also mentioned by Ian:

I tried... I tried the mask on. I couldn't even without being connected. I couldn't even stand that. It has to come off (Ian, post trial)

Here, he simply stated that the mask had to come off and there was no other option. This unbearable experience and the strong feeling against having the mask on his face was further explored by him:

I told Dr.1 at first when I saw it I said, "no way that I can stick the mask on my face". I said, "foreign, alien"... I just couldn't do it. (Ian, post trial)

He described the mask as 'foreign' and 'alien', expressing the impossibility of assimilation with the mask. This description of NIV as foreign may be explored by the example of someone who is in a different country. If someone is a foreigner, s/he will always remain separate and distinct from the native and cannot become the native even though it may be possible to coexist. Furthermore, it was not a matter of preference of not having the mask on, but it was his ability to have it on which was in question: the foreign mask just could not be attuned to him. Moreover, Ian later referred to the mask as 'KGB torture', implying the psychological and physical agony related to NIV. These aspects of his view of the mask hindered him from using NIV and his strenuous effort, emphasised by repetitive use of 'try' in the first quote, failed. While the focus of these patients was on the negative feature of the mask, Matthew described his concern as below:

I don't want to ruin it and I don't want to feel sick. I didn't actually be sick, but it made me feel like I would be. So, I thought I wouldn't use it – better not. I

didn't really like that. I thought 'Well, this is making me worse not better' that's what I thought you see. (Matthew, post trial)

Even though Matthew did not actually vomit, his worry regarding becoming sick and ruining the mask as a consequence, was enough for him to decline the use of NIV. Moreover, this fear of becoming sick with NIV had become a belief that NIV was actually making him worse which is seen in his assertion; 'this is making me worse'. Because of this fear and the belief, he was reluctant to pursue NIV use regardless of his first trial which had taken place without the feeling of nausea. This reaction to prevent a plausible adverse event may be in turn be understood as a way to control the situation and secure his feeling.

For some, it was the air pressure of NIV which caused great fear:

It was forced.... That's what it's like when it winds it's like, you know what I mean, it [unclear] can't breathe. [becomes upset] (Rachel, post trial)

Rachel described a forceful air pressure from NIV which made her feel she was not able to breathe. This frightening experience was also shared by Ted:

I definitely don't want that again. It's just [pause] as if though it stopped me breathing as though I was trying to breathe out and this was blowing back and the wind was blowing out [exhale]. (Ted, post trial)

Ted illustrates how asynchrony with NIV was experienced; this was later explained as a fight to breathe. His breathing was threatened by the machine, which was perceived as stopping his breathing thus his need to fight to breathe. In consideration of the significance of breathing to him, this can be understood that this was the fight to control his life by trying to be in charge of his breathing: the machine was seen to invade the autonomy of his existence thus he reacted against it. Hence, NIV was seen as a hostile machine which prevented him from breathing and robbed him of autonomy. Based on his experience, then, Ted showed no interest in trying NIV again regardless of his theoretical knowledge, having previously been informed by a physiotherapist that NIV would synchronise with his breathing pattern with

acclimatisation. This observation regarding the fear of losing autonomy, consequent of a fear of losing one's breath with NIV, can also be applied to Rachel.

When all of this is considered, their anxiety and belief that NIV would threaten them was found to be influential in decision making. Further investigation as to the origin of this anxiety or fear seems to indicate the ultimate underlying issue. It was understood that their fear or anxiety was the result of their concern over losing their control and autonomy if they used NIV, therefore their withdrawal or declining to use it was the way to retain their autonomy. This concept highlights the fact that a threat to autonomy could be triggered by some of the features associated with NIV.

5.4 Negative experiences with the healthcare service

The next aspect focuses on how emotional distress and disempowerment in individuals can be caused by an interaction with the healthcare service and that this has the consequence of affecting their decision-making. Six participants revealed their dilemma over working with hospitals and these issues originated from a bad experience with healthcare or a poor image of the health service as portrayed by the media. The negative emotion generated as a result of poor interaction with healthcare services was observed to affect how participants engage with the services in order to secure their feelings. Their experience and the image of the health service also appeared to disempower these participants by challenging their sense of autonomy, sense of control over the situation and their sense of security including the very existential aspect. Here, the participants' reluctant attitude towards NIV appeared as the way to prevent further emotional distress and the disempowering caused by interactions with healthcare providers and this impacted their decision regarding NIV.

Both John and Peter reported having received poor hospital services and this was so influential upon them, that neither of them considered a trial of NIV. Moreover, they later withdrew from continuing with the study, presumably due to their unwillingness to be reminded of their experience. This reluctance was already observable with John in his withdrawal from the formal interview process and the field notes from the visit made by another researcher describe this:

When asked about breathing tests he was reluctant to talk about them. He confirmed that this was related to his experiences at the hospital when prompted.

He agreed that this had not been a very enjoyable experience for him and had put him off future visits. (John, pre trial)

Likewise, Peter shares his encounter with the hospital which caused him psychological distress:

Written response: I was agreeable [to have breathing assessments] at first but every appointment since 2006 has been cancelled. (Peter, pre trial)

Peter reported to have been 'let down', 'disappointed', and 'upset' by the repeated cancellations which consequently dampened his initial willingness to attend the assessments. Considering the consequence of both patients' experience, there is plausible psychological distress generated by this poor interaction. At least in the case of Peter, his response of rejecting the NIV appears to be a response to what was perceived as previous rejection from the hospital. It may be interpreted that the cancellations from the hospital generated a feeling of rejection or the sense of worthlessness whenever the appointment was cancelled. Peter actively chose to disengage with the healthcare service altogether to prevent further disappointment and the potential psychological distress this engendered and a similar situation seemed to apply for John.

Similarly, the preference of a peaceful environment expressed by Ted may be interpreted as the way he used to prevent psychological distress, in his case, more specific to the sense of insecurity.

[overlapping with carer] not wanting for mixing or anything a bit of alone type of thing, In a hospital I get frightened of hospital again the all set-up you know so... (Ted, post trial)

From this extract, possible reasons for disliking hospitals may be discussed. Firstly, his private personality is evident in his preference of not being 'bothered' by other people which seems impossible in a hospital setting where regular monitoring is required. This intervention from the hospital may be perceived as an intrusion into his personal territory thus threatening his comfort zone. In addition, his explanation of getting 'frightened' in the hospital may be understood as a display of his insecurity

generated by unfamiliar places, further accelerated by all the ‘set-up’. Therefore, it can be understood that his dislike of hospital is actually not restricted to hospital per se, but any kind of unfamiliar places with other people, this being particularly manifested in a hospital due to the nature of the setting.

For Ian, it was the image related to hospitals which affected his sense of security and discouraged him from going through the trial:

I just really have never liked them [hospitals]. They’re places where you go when bad things happen really aren’t they? You know, when you’re not well and people are dying and things. So, I mean I just don’t like them. Never have.
(Ian, pre trial)

For him, hospitals are the gathering of ill people and he shows his dislike of the idea of going there as an inpatient, for that would imply that he had become one of them. Despite the fact that Ian claims no actual negative experience of hospitals, he seemed convinced that he had a ‘phobia’ of hospitals which, from what he said, appears to have originated from a fear of being one of the ‘dying’, indicating an existential concern. Even though it may be due to his illness, it is interesting to note that Ian did not seem to take notice of those who are treated and recover in hospitals. Hence, it may be argued that Ian avoids hospitals to secure his sense of mortality.

Some interaction with medical staff was also pointed out as a negative aspect of hospital service. This interaction was sometimes perceived to be violating patients’ autonomy. For example, Ian expressed his frustration over the persistent approach of the hospital regarding NIV:

Hmmm,yeah. They’re trying to persuade me, yeah, very much so. I know they’re all at it, trying get me to change my mind – even though really I think it’s my decision. And I have tried to tell them. I do say the same thing every time I go there. (Ian, pre trial)

Ian speaks about the persistent and forceful approach from the hospital, which is seen as an assault on his rights to make his own decision – his repetitive negotiations with the hospital emphasise the sense of invasion by the hospital by apparently challenging his position. His frustration may be observed in his repeatedly neglected statements

regarding NIV. This frustration was further observed where he stated that he wished for the hospital to let him 'get on' with his life and let him 'be', indicating that the hospital was preventing him from living his life as he desired. Therefore, it may be argued that the healthcare service was seen to challenge his autonomy. This impression of intrusion into life and autonomy was also shared by Simon in terms of hospital appointments:

I'm tired of it all already. And it's going to get worse – I don't need all of it. I wish they'd leave me alone. If I haven't [long pause] if I haven't got long, I don't want to spend my time like that. (Simon, pre trial)

The sense of the overwhelming number of appointments is apparent and Simon wishes for disengagement from them even though he acknowledges some of their relevance and values appointments elsewhere. This desire appears to have stemmed from his perception that hospital services are interfering with his quality of life. The sense of loss of his autonomy is presumed from the fact that his schedule had all been planned by the hospital despite his unwillingness to keep the appointments. Furthermore, his account of how he would like to spend the terminal phase seems to indicate his desire to regain his autonomy. Nonetheless, it is likely that the awareness of the ultimate outcome of MND, being reflected by his silence, is the main reason for his desire to be left alone and to have quality of life for his limited time.

Therefore, poor impression of and interaction with healthcare services were found to challenge the sense of self by causing emotional distress and disempowerment in the forms of invading autonomy and the loss of control. Because of these negative impacts on individuals, a reluctance to engage with the healthcare system was perceived which ultimately affected their decision over using NIV. Also, the very nature of MND, that it is a relentless illness without a cure, may have influenced how much individuals wanted healthcare professionals to be involved in their life and that what seemed to be excessive service involvement may have been perceived as interfering with their quality of life, leading back to the issue of maintaining their dignity.

5.5 Not needing NIV

Participants also expressed the perception that they did not need NIV and this view was mostly based on their own observation of their condition. Some did not identify any change in their breathing pattern and thus dismissed the idea of needing NIV, while some others did see the change, yet most of them associated it with other factors and not as a symptom of MND. Also, some participants did not perceive the change as problematic or serious enough to use an aid. Because of their understanding of their symptoms and holding their own explanation for them, most of them expressed their suspicion over the need of NIV as suggested by the healthcare professionals. In consideration of the consistent account of the essentiality of self seen in the other concepts, this seemed to again be a manifestation of the conviction of the participants that they did not need NIV to preserve the self.

The majority of the patients (n=9) were dubious about the need for NIV. Among them, however, different reasons were identified for dismissing the idea: no observed change in breathing, different causation for breathlessness and disturbed sleep, and denial of externally observed poor breathing and disturbed sleep. John witnessed no change in his breathing:

When questioned about his breathing he felt that he had not experienced any change in his breathing and was not having any problems at all. When questioned about the previous symptoms at night mentioned by his wife he denied knowledge of these. He felt he had not had any problems. (John, pre trial)

Since he had no awareness of his breathing changes it was natural for him not to consider NIV as needed to improve his breathing. Yet, his denial of his wife's account in the interview may indicate his denial of the symptoms even if he was indeed not aware of the event: rather than take notice of his carer's observation, he confirmed no change in his breathing. Unawareness of a change in breathing at the point of assessment was also found in Timothy:

I: And had you noticed any changes in your breathing when you were offered the ventilator?

P: [Shakes head]

I: So you didn't feel you needed a ventilator at that time – you didn't think you needed any support with your breathing?

P: [Shakes head]

I: How about now – do you think you need any help with your breathing now?

P:[Shakes head]

I: You still don't feel you need a ventilator?

P: [Shakes head]

I: Or... you just don't want it?

P: [Nods head]

(Timothy, pre trial)

Although he later admitted that he had noticed some current change in his breathing, he did not see a need for NIV. In his case, however, the issue seemed to be his fear and claustrophobia (see the previous section), and his unwillingness to use the NIV was apparent in the interview.

In comparison to John and Timothy, some others acknowledged their poor breathing or disturbed night. For example, Rachel identified disturbed sleep:

Yeah. [patient coughs] It's um.... because I'm lying in [unclear] position all night, I'm lying on me arm and it starts hurting that's why I have to... I wake up to move me arm [voice getting weaker]. (Rachel, post trial)

Rachel described the sleep disturbance as caused by pain in her arm. As her condition had deteriorated she did not have the strength to manoeuvre in bed so to change position while she is asleep, instead she needs to wake up and reposition herself. For her, it was not a problem caused by the weakened chest muscle or respiratory problem as healthcare professionals may suggest, but a pain in her arm, hence NIV was not needed in her opinion. Other patients also share the view of not needing NIV since there was no problem:

I mean actually my own breathing is quite good; I do get slightly breathless if I have to do too much, and if I get upset, but actually it doesn't cause me any problems or any worry or any kind of, um, it doesn't upset me. I mean, I'm usually just sat here during the day or I'm in bed and it doesn't cause me any

problems here or in bed, I'm quite comfortable in bed. I mean, the reason I think they wanted to check my breathing was because I was having this little bit of breathlessness – but since [doctor4] has started me on these anti-depressants, actually it's almost completely gone. (Catherine, pre trial)

Catherine acknowledged her breathless condition, yet she shows little concern and states that it is actually 'quite good'. This is due to her perception that her breathing is not causing her problems: breathing becomes problematic once it started to trouble her or upset her. It is interesting that she mentioned 'upset' as an outcome of possible breathing problems rather than 'worrisome'. This is in line with the points discussed above, that her dignity is her main concern regarding NIV use thus the acceptability of the condition. It can be understood, therefore, that breathing is not an issue for Catherine unless it causes emotional discomfort. Moreover, she argues that her previous breathlessness was caused by anxiety and she reports that the breathlessness had been completely resolved after she started taking anti-depressants. This claim of complete absence of breathlessness is somewhat different from her initial account of her breathlessness being unproblematic, dismissing any experience of breathlessness all together. However, this may be understood as an emphasis on her improvement in breathing rather than her contradicting herself. Therefore, it can be argued that her main problem was not breathlessness caused by MND, but emotional disturbance. Apart from the impact of her psychological condition, Catherine refers to the impact of the environment (i.e. her comfortable bedroom) which also seemed to have greatly affected Ted:

I'll go and listen to him [at the clinic] but if it was for trying that thing [NIV] I wouldn't want to try cause in me own mind I don't think I need it you know. Because I haven't got a sleep [unclear] I sleep for the three hours and I wake up but at least now I'm going back sleep before I wasn't and it was in the other house. (Ted, post trial)

Ted attributes his sleeping problem to the poor environment of his previous house and claims that the new environment had improved his sleeping. Although he seems to imply a slight problem with sleeping time, the improvement in his sleeping is significant, therefore he denies the need for NIV. For him, the ability to go back to

sleep secures his quality of sleep and gives him confidence that NIV is not necessary. However, it may also be influenced by his willingness not to try the mask and to engage with the hospital as discussed above. He shows openness to the medical consultation by going along to the clinic, yet it is apparent that his 'mind' had already been made up considering his perception of the sleeping improvement. In addition, Ted backed his argument with the comment from the doctor:

You'll need in time you know this isn't for now but supposing a time you might need this type of thing. (Ted, post trial)

By citing his doctor to support his argument, Ted repeatedly expresses NIV as a surmised event. While the comment from the doctor was used by Ted to emphasise his argument, comments from professional carers were often seen to raise questions in patients.

it was difficult to clear my throat and it was difficult to cough and clear it, to clear my throat. So, my breathing, well, it wasn't my breathing that was the problem. When she [doctor] said it, I thought 'Oh' you know? (Simon, pre trial)

In the case of Simon, the possible involvement of breathing with MND came to his awareness when a breathing test was mentioned to him. However, as seen in the quotation, Simon denied any problem with breathing when the test was mentioned. When asked about his current breathing, Simon admitted the change, yet still did not perceive the need of NIV:

I do occasionally [get short of breath]. But I have a spray for that, to help me if I feel my breathing is slightly short. I have a spray for that. So, because I can use that, I don't have any concerns at all about my breathing really. (Simon, pre trial)

It can be interpreted from the quotation that Simon occasionally experienced more than mild breathlessness which needed addressing. However, a spray originally prescribed for his asthma effectively cancelled the impact of breathlessness, thus he

reported no concern over his breathlessness: his breathing was recoverable and manageable with his inhaler. It is interesting to note that his confidence with his breathing is conditional on the availability of the spray, which seems to suggest that an ineffective spray would make a difference in the situation. Even though he argues that this is manageable breathlessness, it may be suggested that his attempt to maintain his breathing by using the spray reflected his resistance to being 'hooked up' to NIV.

Other patients also shared their doubts about the need of NIV while acknowledging the change in their breathing and sleeping:

I'll try anything if it will help me. But the thing is you see is that some days I'm alright getting out of the chair and some days I struggle a bit. So I think do I really need a chair? It's like that a bit with the breathing as well, some days I feel better than others, so I think 'Well, do I really need a machine?' because they did these overnight tests, but what if they were just one of my bad days and the rest of the time I could be alright, couldn't I? So I don't know about all these new things coming to me. (Matthew, post trial)

Even though Matthew showed his willingness to employ aids, he questioned their necessity. He seems to imply that he would not want aids until his symptoms had become permanent. Therefore, his willingness to use aids may be understood to be conditional, indicating his resistance to aids, which possibly reflects the idea in his previous extracts that he values independence. Also, his definition of good days and bad days, which are based on his experience of the days, is seen to be superior to the overnight test, presumably because of the daily assessment compared to the one off assessment. This doubt regarding the credibility of hospital assessment was shared by other patients, with one patient even carrying out his own assessment for confirmation:

Yeah, yeah. Well, it's pretty stable. You know, it's stable on that thing. I've taken a few this week and it's been stable. (Ian, pre trial)

After being recommended that he use NIV, Ian started his own breathing assessment with a peak flow meter and this behaviour was probably due to his desire to avoid a

trial of NIV. The stable results obtained from it gave him a complete confidence in his stable breathing. It is interesting to note, however, that his account of 'stable' was presumably defined by his own breathing standard rather than having any reference to a medical standard, while his behaviour implies that he recognised the importance of some medical assessments to measure his breathing function. For Ian, his breathing had been proved to be ok and the evidence was further confirmed by his own measurements taken on more than one occasion.

In contrast to these patients whose arguments were based on their understanding of their condition, Henry declined NIV after a medical consultation. In addition, Henry appreciated the benefits of NIV and used it for some time until his condition dramatically changed:

Now they've [doctors] told me that I don't have to use it [NIV]. (Henry, post trial)

In consideration of the progressive weakness outweighing the benefits of NIV, Henry declined the treatment as it had stopped being effective and the focus of his treatment was presumably changed to the management of dying from management of symptoms.

All considered, the majority of patients asserted NIV as not for them since they did not perceive the need for it. Their arguments were mostly based on their own observations or explanations of their condition and this was still observed even when their perception was contradicted by their health professional. Their rejection of the need of NIV, whatever the reason, in turn seems to be the way to preserve the self by avoiding NIV use and what is involved with the treatment.

5.6 Overall hermeneutic circle

The analyses were presented within four concepts. Although each concept manifests a different perspective this experience leads to a rejection of the idea of using NIV, the key point was perceived to be the maintenance of the self, which implies autonomy, dignity and quality of life. Throughout the transcripts, the importance of self and the effort to maintain a sense of self were observed.

Firstly, the sense of self may be affected by the illness itself, which threatens patients' autonomy, dignity and quality of life. Because of the sense of losing control

over these aspects, patients may become reluctant to engage with NIV, a treatment which is identified to further threaten their self. Secondly, some features of NIV were perceived to challenge their autonomy, generate insecurity, and impair quality of life, thus negatively affecting their decision-making. These underlying motives were often expressed in the form of fear and anxiety. Thirdly, unpleasant interactions with the healthcare service were perceived to be assaults on the self, causing emotional distress and disempowerment to the patients and as a result a general desire in the participants to avoid interaction with healthcare. Finally, the perception that NIV is not necessary was also found to be closely related to their sense of self. It was observed that the participants attempt to preserve the self by rejecting the idea of needing NIV.

Therefore, the important role of the self played in the decision making process in this particular group was acknowledged. The detail of their negative responses to NIV differed, yet all the accounts demonstrated that what mattered in their decision making stemmed from the same concern: maintenance of the self. This general finding reaffirms that an idiographic approach reflected by hermeneutic practice was crucial in understanding these particular individuals in the particular setting of decision making regarding NIV in the context of MND.

5.7 Summary

IPA was conducted to explore the underlying reason for declining or withdrawing from NIV in a particular group of individuals with MND. The reasons for NIV withdrawal were explained from four different aspects: preservation of the self, personal perception of intervention with NIV, negative experience with the healthcare services, and not needing NIV. Table 5 presents the four identified concepts with their themes and sub-themes, and was used as a master table.

The first concept highlighted the impact of the illness on people's perception of their identity, which often involves a struggle between the old and the new identity. The main concerns related to the new identity were perceived to be impaired autonomy, dignity and quality of life. The significance of breathing and the implication of its deterioration were also recognised and extending their life with the inferior identity was not welcome.

The second concept focused on how NIV was perceived by the participants. Some features in particular were seen to be negative and found to generate fear and

anxiety. In addition, this fear of harmful outcomes was further observed to form a belief. While individuals did not always refer to the same feature of the NIV as causing fear, their experience of the threat to autonomy was common as a reason for non-engagement with NIV.

The next concept addressed was the impact of a negative experience with the health service which may be based on their actual experience or an image. Regardless of the origin of their negative impression of the service, it was acknowledged to have created discomfort and damaged the notion of self. A reluctant and passive attitude towards engagement with the healthcare providers in consideration of NIV treatment was thus displayed.

The last concept showed how individuals understood their condition and their need of NIV. In terms of their condition, most people either did not experience any change or did not perceive change as problematic. Those who did not perceive changes as problematic, described changes as inconsistent, attributable to other factors, or manageable. Hence, they did not acknowledge the need for NIV. These accounts against the need of NIV were generally understood to be a manifestation of their unwillingness to use the treatment.

Although some accounts were from pre-trial NIV, available transcripts provided sufficient data and they were found to concur with each other on factors leading to non-engagement with NIV while retaining individual colour. These concepts were arranged to illustrate plausible aspects relating to declining or withdrawing from NIV, yet it was recognised through the detailed analysis that the underlying concerns may be generally narrowed down to one fundamental feature: the maintenance of the self. While this fundamental element reflects the argument of shared essence of being as argued by Heidegger (1962), it is important to note that these concerns were in turn formed by their perception of phenomena; thus the necessity of a case-by-case approach/analysis is also reaffirmed. IPA was used therefore to understand how individuals experience the process of decision making regarding using NIV and the eventual decision to not accept NIV.

Table 5: Master Table

Concepts	Themes	Sub-themes	Participants
Preservation of the self	Identity	<i>Damaged identity</i>	Catherine, Matthew, Simon
	Preservation	<i>Autonomy</i> <i>Dignity</i> <i>Quality of life</i>	Catherine, Matthew, Simon Catherine, Ian, Simon
	Breathing	<i>Significance of breathing</i> <i>Autonomy of breathing</i>	Catherine, Simon Catherine, Simon
Personal perception of intervention with NIV	Image of the features of NIV	<i>Mask</i> <u>Sound</u> <u>Alien</u> <u>Appearance and practicality</u> <u>Claustrophobic</u> <i>Air Pressure</i> <u>Shocking</u>	Catherine, Simon Ian Matthew Timothy, Ian, Ted Matthew, Ted, Rachel
	Reaction to NIV	<i>Fear</i> <i>Unbearable</i>	Matthew, Ted Ian
	Belief	<i>Unable to wear the mask</i> <i>Machine worsen the condition</i>	Ian, Timothy Matthew
	Threats to autonomy	<i>The loss of control</i>	Ian, Matthew, Ted, Rachel
	Impression of hospital	<i>Dislike of hospital</i> <i>Poor image of hospital</i> <i>Preference of peaceful environment</i>	Ian, Matthew Ian Ted
Negative experience with the healthcare services	Bad interaction with hospitals and its outcomes	<i>Emotional damage</i> <u>Withdrawal</u> <u>Rejection</u> <u>Confusion</u> <i>Disempowerment</i> <u>Invaded autonomy</u> <u>Loss of control</u>	John, Peter Peter Ted Ian Simon
Not needing NIV	Changes	<i>Breathing</i> <u>No change</u> <u>Change</u> <i>Sleep</i> <i>Denial?</i>	John, Timothy Catherine, Ian, Matthew, Simon Ted, Rachel John
	No significant changes	<i>Different causation</i> <i>Luck</i> <i>Evidence of stable breathing</i> <i>Solution for the changes</i>	Catherine, Ian, Matthew, Ted, Rachel Matthew, Ian Ian Simon
	Suspicious about the need of NIV		Catherine, Ian, Matthew, Ted, Rachel
	Comments from doctors		Simon, Ted, Henry

CHAPTER 6

Discussion

6.1 Introduction

The aim of this study was to understand the experience of making a decision about using NIV and the issues which eventually lead participants to decline or withdraw from treatment with NIV. In order to do so, I took advantage of the opportunity to interview and listen to these volunteer MND participants and attempted to comprehend their experience using the methodology of IPA with the intention that their voice would be heard as they described their views. An understanding of the issues is valuable as a third of the patients who were willing to have their experience mapped declined the intervention, while 49% of other participants in the main study continued to use NIV. Insight into this could be anticipated to help healthcare providers understand the impact of the procedures involved in assessing patients and establishing them on NIV, if not the whole phenomena of the impact of this diagnosis. An understanding of phenomena as experienced by individuals, rather than only that of a physiological aspect, deepens insight into the issues and hopefully enables healthcare professionals to provide an appropriate engagement with patients.

In the last chapter, the main concerns regarding the use of NIV and the decision to decline it were discussed, with an interest in exploring how certain aspects could become determinants to their decision making. The findings from in-depth interviews, with an effort to interpret the accounts by using IPA, identified four influential aspects that affect decision making: preservation of the self, personal perception of intervention with NIV, negative experience with the healthcare services, and not needing NIV. Furthermore, these concepts were found to be fundamentally affected by how individuals understood the phenomena in relation to their sense of self. These findings are discussed in the context of the literature review in this chapter. The chapter also includes my reflection of the strengths and limitations of the study.

6.2 The pattern: the influence of the self in NIV declining and withdrawal

The understanding of the significance of self by the participants was central. In the current study, the term ‘self’ focuses on autonomy, dignity, and quality of life as its

components and these three aspects were perceived to be influential in how participants evaluate their experience and impact of using NIV. Factors related to NIV which were seen to be threatening or challenging to the self included induced psychological distress or emotional reaction and NIV was ultimately dismissed in order, I believe, to maintain the self. Although the main focus of the impact of the self was explored within the framework of decision making regarding NIV use, it was also apparent that the general concerns of the participants regarding the illness impacted on the self. In that aspect, therefore, their decision about the use of NIV seems to manifest their general response to the illness, bringing me back to the hermeneutic circle. Hence, this understanding of the pattern may be used primarily to comprehend the experience of this cohort in terms of non-engagement with NIV, yet the understanding may also be used to address other phenomena related to the illness.

6.3 Preservation of the self

About half of the participants expressed significant frustration over the physical changes due to MND. They reported that the physical changes obliged them to give up their previous habits and independence which used to shape their identity and their sense of self. In this context, NIV was seen as an instrument to further challenge the self by making them live longer with the new undesired identity, thus invading their autonomy.

A characteristic of the new identity was a degree of helplessness, because of the physical restrictions, resulting in negative emotional responses, and even with a negation. This type of emotional reaction caused by the loss of independence is known to be common in other illnesses, not only in MND, and the impact of the changes on the perceived self, which is distinct from the individual's knowledge of the reality of the self, have been reported (Dickson *et al.*, 2008; Hugel *et al.*, 2006). As observed in the present study, this loss of independence is reflected in their need for care and this was seen as a manifestation of their dependence (McPherson *et al.*, 2007). Therefore, the loss of independence may be argued to emerge from both internal and external factors. 'Internally', the loss may be acknowledged by the individual because of their inability to perform the previous activities, or 'externally' it may be emphasised by having to have other people to care for them. Hence, it may be claimed that any kind of physical change which impairs people's ability to practice

their previous activities create a sense of the loss of self, leading to psychological disturbance.

Concerns over their physical state and dependency in the future were also pronounced and life with NIV was seen to be undesirable. The main reason for this reaction was found to be driven by their perception that there would be no real living or life with NIV, but only a preservation of cognitive function, if at all. The image of being totally dependent on NIV was emphasised and subsequently despised. Those who shared this view indicated that there is an acceptability of the condition of the living status and one with NIV is not one of them. Their concerns were their perceived quality of life and dignity. From their accounts, it was understood that a life that gives them a sense of living has quality of life and dignity and such life is gained through preserved autonomy. Although the make-up of the sense of living varies and is not static, it was found to be essential and has also been reported by other studies of people with terminal illnesses (Bolmsjo, 2001; Carter *et al.*, 2004). Moreover, as is true in the current research, the previous studies report that some patients may even prefer to hasten their death rather than lose their dignity (Bolmsjo, 2001; Terry *et al.*, 2006). This indicates the close relationship between dignity and the quality of life: dignity as a key determinant of quality of life. For that reason, just as quality of life and dignity were vital to the participants, NIV was felt to counteract the values they held.

6.4 Personal perception of intervention with NIV

Seven participants in the study vocalised their concern in relation to some features of NIV and these concerns were understood to be generated as a result of fear and a belief which in turn reflected their threatened autonomy.

The preconception of an inability to use NIV was found to be influential on individuals' reaction to NIV. The study showed how belief could be formed by the fear of a threat to autonomy thereby making participants continuously reluctant to try NIV. Such an idea or belief affecting the way people approach treatment decisions was also reported by Benson and Britten (2002). Looking at the consumption of medication, Benson and Britten (2002) found that people tend to form their perception based on their former experiences. In their study, some individuals were found to hold the view that medications are unnatural or unsafe and thus were reluctant to take them.

Together with their observations then, it can be argued that patients may have generated certain beliefs about NIV prior to their actual contact with the machine and that their perception is influenced by their preconceptions of NIV or their previous experience.

Some of the negative elements and their psychological consequences reported in this study, such as a panicky feeling caused by the air pressure, were the same as those mentioned by Lindahl *et al.* (2005). However, the dominant negative feature expressed by the participants was the mask which had also been reported as an issue and widely addressed in the sleep study. In fact, the feeling of being claustrophobic was shared by a few patients in the current study and had previously been recognised as a cause of poor adherence to ventilation (Charsens *et al.*, 2005). As already mentioned in the previous chapter, Torheim and Gjengedal (2009) argue that the claustrophobic feeling is the manifestation of anxiety and insecurity created by the impression of the lack of control over the situation and is thus associated with the feeling of being powerless and vulnerable. In line with this evaluation of the role of the sense of control, Wild *et al.* (2004) found high adherence in individuals with higher self efficacy in comparison with those with lower efficacy. These findings are resonant with the present interpretation that the autonomy of individuals is essential and that a perceived lack of control over the machine would lead individuals to become reluctant to use NIV. Moreover, it may be further argued that the threat to autonomy generated by NIV may be perceived to be even more prominent because of a previously damaged sense of the self due to the physical limitation caused by the illness.

6.5 Negative experience with the healthcare services,

More than half of the participants (n=6) shared negative perceptions of the health service and these were sometimes based on their image of hospital, but usually stemmed from their previous or current experience with services. Their concern was regarding an involvement of the healthcare service in NIV treatment, either with an organisation or with professionals themselves. Their experiences with healthcare providers had generated psychological distress, such as fear and disempowerment with regards to their security, autonomy, dignity, and quality of life.

Because of the significant impact on their psychological well-being, this study recognises the importance of good relationships between patients and healthcare providers just as it has been identified by others (Hughes *et al.*, 2005; Shattell, 2004). In the present study, the significance of this as an unmet need was particularly manifested in two participants who declined the treatment without a trial because of the trauma from previous interaction with the healthcare service. Due to the psychological distress generated by their previous interaction, it was understood that their decision to decline NIV was taken to prevent further possible harm. In accordance with this argument, Coyle (1999) identifies poor treatment by healthcare service to be a challenge to self-value and argues that the 'devaluation' generated by the service is one of the factors causing dissatisfaction in the service users, eventually leading to an identity threat. Therefore, it may be argued that the two decliners experienced a devaluation of self which led them to engage with the passive attitude to protect it. This finding on the threat to identity was also recognised among other participants where they reported the invasion of their autonomy, the loss of control and quality of life, which were acknowledged to be essential in their sense of self.

Coyle (1999) described the loss of control to be related to disempowerment in patients. Although Coyle's (1999) model on 'disempowerment' involves three components: treatment, social role and personality, the first element is the one particularly relevant to the current study. Coyle (1999) argues that disempowerment occurs when control over treatment was perceived to have been snatched from individuals rather than voluntarily given up by the patients. This deprivation of decision making was seen to be significant, leading to the sense of the loss of control and vulnerability. This concept of disempowerment was found in the current study where participants felt that they were not heard by the healthcare professionals in terms of their interest in NIV treatment and thus their right to choose was perceived to be violated. Similarly, the overwhelming effect of appointments, also previously identified as a burden (Gysels *et al.*, 2007; Hugel *et al.*, 2006), depicts the participants' experience of being disempowered by not having control over appointments without a chance to have their say. Even though in some cases it may be that patients feel it inappropriate to question or dismiss the suggestions made by healthcare professional (Pollock *et al.*, 2008), some unsuccessful attempts to vocalise their opinion found in this study should be noted. Out of these experiences, then, it was understood that the sense of the threat to identity made participants feel uneasy

about their interaction with the healthcare providers and even drove them away completely. This outcome from the interaction is opposite to what is desired by patients, namely being respected and valued (Shattell, 2004). This attitude towards the healthcare service was then reflected in their reaction to NIV treatment.

6.6 Not needing NIV

Almost all the participants (n=9) questioned the essentiality of NIV based on their own understanding of their condition and over the particular issues of either breathlessness or sleeping pattern. The main factors contributing to these views were perceived to be a lack of discernable change, even when informed of it from physiological measurements, the perception that the change was not problematic, or having an explanation for the condition other than MND. Because of these explanations, NIV was seen to be unreasonable and was ruled out.

With regards to those patients who did not see changes as problematic, the possibility of an unconscious attempt to prevent breathlessness may be first mentioned (Gysels, 2008). Gysels (2008) found undetected breathing change in individuals with chronic obstructive pulmonary disease. It was argued that the change was not noticed because of the gradual increase of breathlessness in their daily life at a slow pace, which was thus covert. The changes were there, yet not actively identified as problems. In the same way, it is not unreasonable to consider that patients start off becoming short of breath, but unconscious adaptation of their lifestyle then took place which masked the breathing change. Secondly, becoming breathless was not expressed as problematic by patients as they did not see it as having a great impact. In agreement with this, the previous study highlights the importance of personal understanding of the phenomena and reports that admittance of change and awareness of the need of help are crucial in a decision making process (Gauthier and Swigart, 2003). This argument was observed to be true in a study of patients with a history of an acute heart attack (Pattenden *et al.*, 2002). They found that the participants, even with the history of at least one heart attack, were not willing to admit the symptoms of myocardial infarction and denied the plausible problems of the symptoms until they became too severe. The tendency to not acknowledge breathlessness as problematic was also observed in the present research. Furthermore, the finding of the present study suggests that this tendency may be due to their

confidence in their ability to fix the problem of breathlessness. Similarly, confidence in their ability to work out the situation has been previously pointed out to be one of the reasons why individuals would not seek medical help (Prins *et al.*, 2008). Another reason identified for not seeing breathlessness as a concern was based on their alternative explanations for their condition. This attribution to a different causation is often observed when people describe a particular event in order to make sense of the experience they are facing (Gysels, 2008; Horrocks *et al.*, 2004). For example, Harrocks *et al* (2004) found that the urinary incontinence found in the elderly was perceived to be a natural course of aging among this group therefore no attempt was made to seek medical help for it.

The previous studies and this work seem to suggest a general trend in this group of unwillingness to seek external help or to accept changes. In order to consider such inclination, the model introduced by Gauthier and Swigart (2003), discussed above, may be rehearsed again. According to their model, evaluation and admittance of an individual's condition, adaptation, and active engagement for future preparation determine the way people make decisions. Applying this model to the current study, then, it may be argued that the participants were reluctant to engage with the treatment because they had not admitted their own condition and its consequences or they were unwilling to adapt to the changes and accept their need of aid. The need for NIV was dismissed mostly because they did not perceive their condition as problematic, if at all. It is interesting to note that most participants acknowledged changes and to some extent accepted them, yet showed a reluctance to acknowledge them as a symptom of MND. It may be argued that this tendency is related to their attempt to maintain the self, which had been affected by MND.

6.7 Limitations and strengths of the study

The in-depth interviews enabled me to understand plausible reasons for NIV withdrawal, yet the limited nature of the access to post-NIV trial accounts, due to the progressive prognosis, necessitates some caution. Although available post-NIV data from other patients showed overall agreement with this analysis, additional themes may emerge from more post-NIV interviews. Also, almost all of the data presented here was collected from patients who had declined or withdrawn from NIV treatment at an early stage; only one patient had used NIV for some time before withdrawal.

Therefore, further study should include patients from different stages of NIV use to assess whether the reasons identified in the current study are still applicable and furthermore how patients who continue on NIV cope with the identity and dependency issues identified in this study. Finally, the less selective homogeneity may be recalled, which may have affected the findings of the study by either overestimating or underestimating the impact of the phenomenon.

A perceived strength of this study was the rapport developed between participants and the interviewers. Since the main study was designed to be longitudinal with regular visits, 7 out of 10 patients reported in this thesis had more than one visit. The multiple visits enabled the former researcher and myself to build up a good relationship with the participants, which, I believe, made them at ease and able to talk about their experiences. This advantage was observed to be particularly important with individuals like Ted who described himself as a shy person. In fact, his carer recognised that he was more relaxed at the second visit and more talkative compared to the first visit. In addition, an active listening to their experience may be argued to have animated their sense of autonomy and made them feel that their dignity was respected. Presumably because of the lack of threat to their sense of self, patients seemed to talk freely and sometimes displayed signs of trust in the researchers. These factors were all believed to have contributed to their openness during the interviews which was valued (Smith *et al.*, 2009).

6.8 Summary

The findings of the current study were discussed in the context of the previous research. Both the current study and the literature acknowledge the essentiality of the sense of self and it is understood that individuals' experiences are evaluated by their perception of the event in consideration of its impact on the self. It is likely that their sense of self had already been challenged by the illness which was further manifested by an introduction to NIV. Therefore, it may be argued that their non-engagement with NIV is a demonstration of the vulnerable inner status already caused by MND.

CHAPTER 7

Conclusion

7.1 Introduction

I have presented my interpretation of the participants' experience of NIV and the reasons for their withdrawal in the previous chapter. The findings were then followed by discussion in the context of a literature review. Based on the findings of the present study, practical recommendations and future research suggestions are proposed in this chapter. Finally, concluding reflexive notes as well as my overall views on this study are shared.

7.2 Implications and recommendations for practice

The findings point out the importance of identifying an individual's perception of the self, if one is to understand a patient's decision regarding using NIV. Although the significance of the self was identified to be invariably valued by individuals, there was a perceived difference in their specific concerns regarding NIV engagement. In order to comprehend the decision of non-engagement of NIV so to provide appropriate care, it is suggested that healthcare providers spend some time investigating what is the main concern of the patient. The suggestions presented below are primarily concerned with the security of patients' sense of self rather than to promote NIV use, which may take place as a result.

Some individuals may be reluctant to engage with NIV due to their unwillingness to live with an impaired identity and fear of becoming dependent on NIV. The issues with the sense of impaired identity and perceived life with MND need to be addressed not only for the purpose of NIV use, but more importantly for the patients' quality of life. Even though some people may tackle these issues by attempting to maintain their identity by keeping previous activities going (Hubbard *et al.*, 2010), this is neither realistic nor ideal in a MND population whose physical ability relentlessly deteriorates, thus the reminder of impairment might only create psychological distress. Among this population, a reformation of their perception may be suggested, which empowers individuals by encouraging them to differentiate themselves from the illness to retain their sense of self (Aujoulat *et al.*, 2008). Once

the sense of self is separated from the illness, their concept of the self may be altered and consequently good quality of life could be attained. Alternatively, if they are concerned about the quality of life with NIV, appropriate education may be given to explain that NIV use is not recommended 24 hours in standard UK ventilation practice. Nevertheless this may not alter their point of view unless they perceive benefits to outweigh their concern regarding becoming reliant on NIV.

In terms of their fear of using NIV, an understanding of the origin of the fear or belief should be sought first in order to comprehend the patients' position regarding NIV and this information needs to be shared among the key carers, both professional and lay. Also, the plausibility of threat to autonomy should be suspected when individuals display fear or discomfort with NIV, as that may indicate their sense of powerlessness or vulnerability. It is also suggested that the impact caused by the illness should be acknowledged, in order to understand how individuals approach the use of a ventilator. Some kind of session such as cognitive behavioural therapy may be offered to help patients understand the psychological mechanism of their reaction to the machine. However, this should only be carried out if patients display their willingness to try NIV. Also, practical alterations such as a change in the type of mask or level of air pressure should be made by professional carers to moderate the impact of the machine.

As mentioned above, a better relationship between patients and the healthcare service needs to be sought. The regular evaluation of the service or training sessions for healthcare providers may be suggested to minimise any negative outcomes experienced by the service users. It is plausible that better communication would improve most concerns held by patients regarding the service. For example, an active involvement of patients in arranging their care plan is likely to increase the sense of autonomy and improve quality of life. Although some negative images of healthcare services may remain due to the media and preconceptions, an attempt to understand the origin of these views may be possible through effective communication. In addition, dislike of hospital settings, as reported by one patient, may be played down by, for example, the arrangement of a private room.

Lastly, an appropriate explanation of their condition should lead to a better understanding of their condition. However, particularly given these findings, clinicians should be alert to identify a genuine lack of knowledge or an attitude of denial towards their symptoms, for the latter is likely to be their effort to maintain

their sense of self by not accepting their need of aid. The patient's view should be respected and their probable underlying issue of their sense of threatened self needs to be addressed.

As seen, the underlying reasons for the withdrawal need to be acknowledged and this should provide a basis for an appropriate engagement of the patient. Although healthcare providers may argue that NIV treatment can benefit patients, especially in terms of survival improvement, this study indicates that such treatment is not always perceived to be the best for some individuals. Since some of the reasons for declining and withdrawing from NIV involve their concern for their sense of self, it is arguable that some individuals may never welcome NIV and that this should be expected. However, some other issues, such as the sense of the loss of control if NIV is used, may be sought to be resolved if patients show continued interest in using NIV. It is suggested that healthcare providers approach individuals sensitively and be particularly careful with those who display any kind of worry or fear over engagement with NIV in order to find the best care plan. This having been said, I believe that it remains of paramount importance that patients views and autonomy be acknowledged and so respected, allowing them to maintain their sense of self whether an intervention is accepted or declined.

7.3 Recommendations for further research

As mentioned above, the study had the limitation of obtaining data from after a trial of NIV as well as different stages of withdrawal. Therefore, it is suggested that further data from different times in the patient journey with NIV be collected to compare the pattern of reasons for withdrawal. It will also be interesting to see if individuals maintain their decision at a later time, though probably only those with a slowly progressive type of MND would have time to change their view. Similarly, it would be of interest to know if there are any circumstances or change in patients' understanding which are influential enough to have them change their position. Also, the similarities and differences of those who use the ventilator may be compared with and it would be of particular interest to explore any different pattern of the perception of self. This comparison may further highlight the reasons for NIV withdrawal and the factors involved.

An advantage of using IPA to conduct these studies may also be expressed. The use of IPA enables researchers to address an overarching theme of any phenomena, yet still value the individuality of people's experiences. This style of approach should be encouraged especially in a study like this where the focus is the individual's experience and their perception of events. I believe that only in this way may the real impact of particular phenomena be appropriately evaluated.

7.4 Concluding reflexive notes

The reasons behind declining or withdrawal from NIV treatment had more significant meaning for the participants than I initially expected. For the participants, their reaction could not be explained by observational logical explanations of the event and this seemed legitimate when I came to understand the implication of the use of NIV and what is involved in the process of its establishment. Quite different from my original view on NIV, which was that the machine is beneficial, these participants have revealed other perceptions of the machine in relation to their quality as a human being. It may be that people sometimes choose not to have efficient aids for their physical conditions since an improvement in physical condition does not always lead to psychological well-being. In fact, these participants seem to indicate that the concern for their psychological well-being surpasses that of their physical well-being. The opportunity to explore these individuals' experiences demonstrated the complexities of humankind and how the situations are evaluated when individuals are faced with MND, which in turn affects their decision making process regarding NIV.

7.5 Concluding comments

The employing of IPA has allowed me to understand why people decline or withdraw from using NIV. I believe I was able to bracket off my initial view that a significant survival gain for MND patients offered by NIV was desirable, to come to an understanding of the key drivers of decision making in this group of patients. The combination of phenomenology, hermeneutics, and idiography was suitable for exploring their accounts of the particular experiences of going through deciding about NIV, in the context of having MND. This approach led me to the identification of plausible reasons for withdrawal, with an identified invariant underlying issue: a

threat to their sense of self. This sense of self seemed to have affected how participants understood their experience and in turn how they made their decision. The main issues with NIV use were recognised to be how their sense of autonomy, dignity, and quality of life are perceived to be affected by the machine. These three aspects, therefore, indicate the importance of a secure sense of self. Furthermore, this sense of self was not only perceived to be relevant in terms of NIV use, but also in how they understood the phenomena of living with MND.

Based on the findings, I argue that it is crucial to understand the psychological dimension involved in decision-making regarding the use of NIV treatment and would suggest a further holistic evaluation if NIV is declined. It is recommended that such evaluation is carried out individually in a way that respects the individual patients' sense of self.

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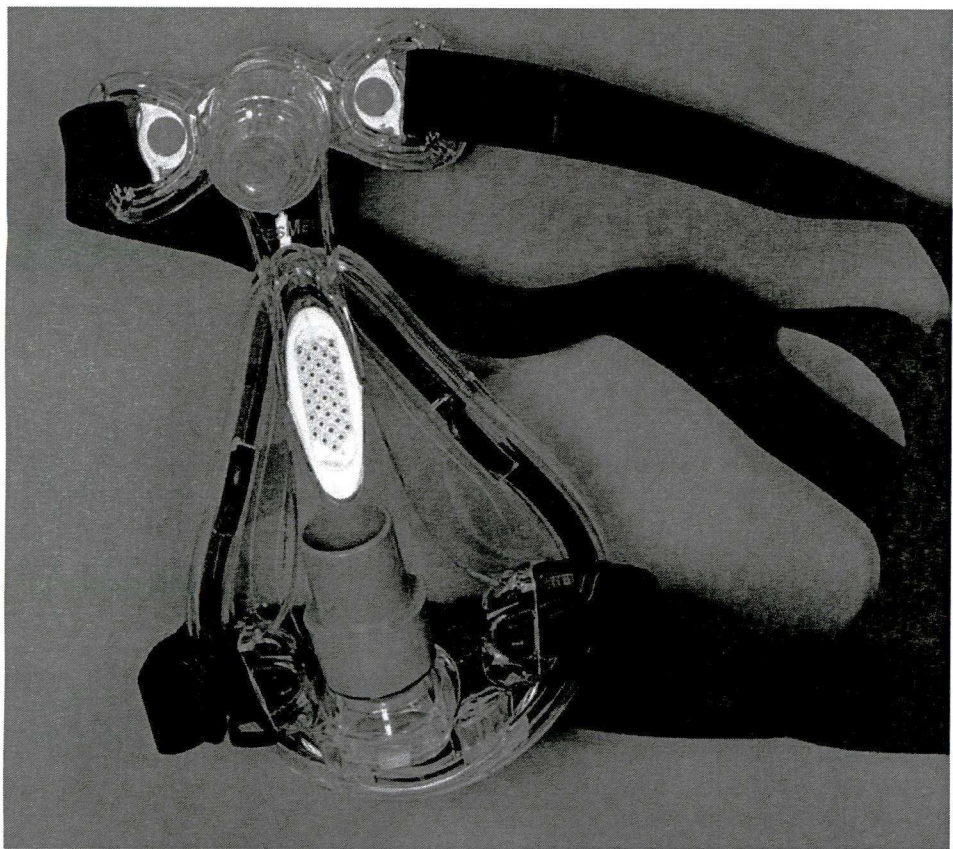
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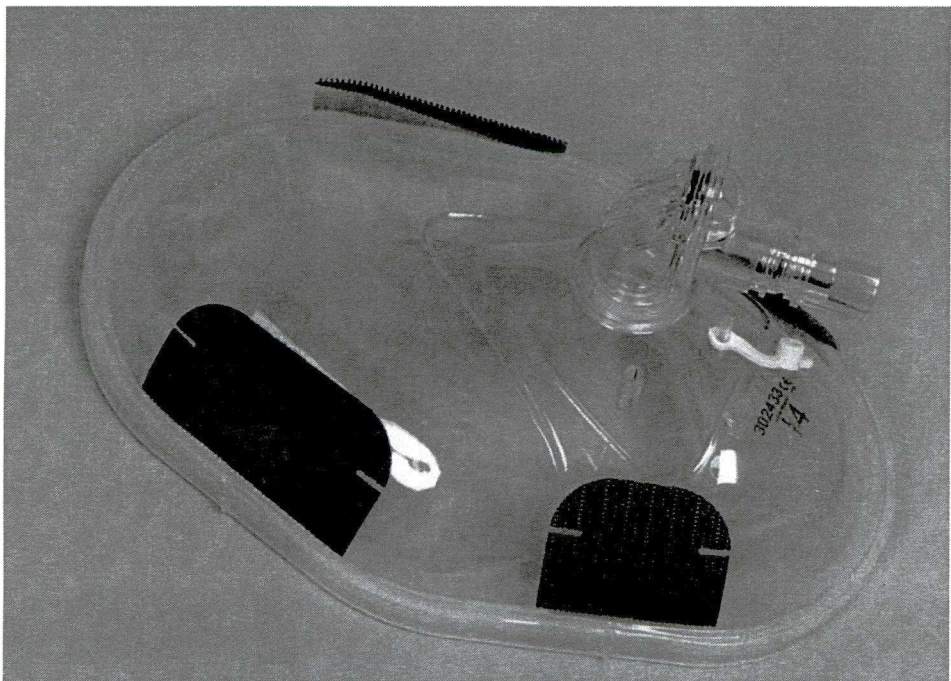
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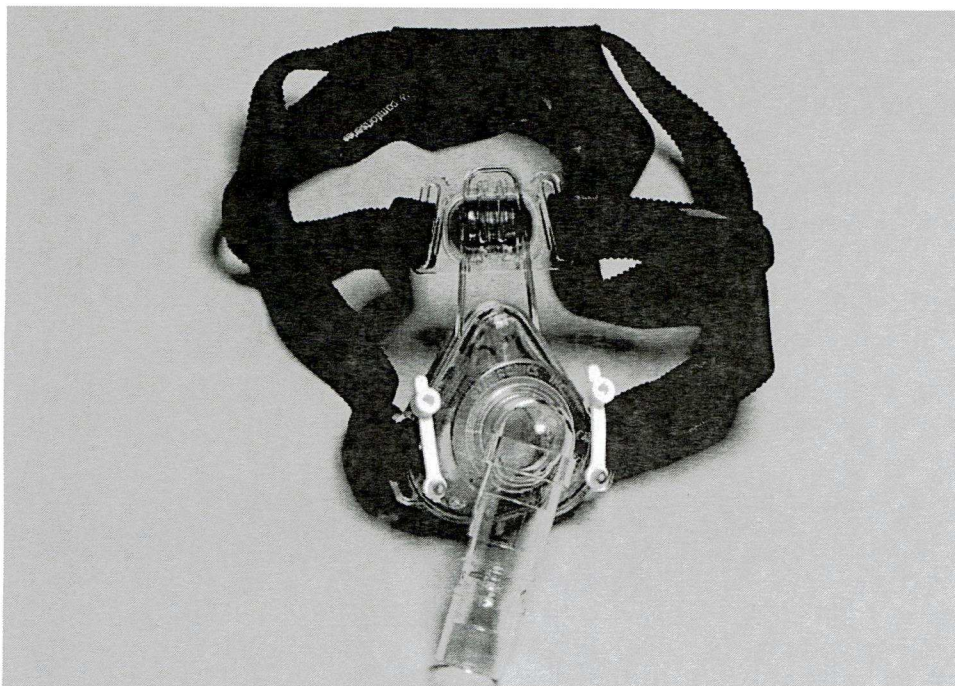
Appendix 1



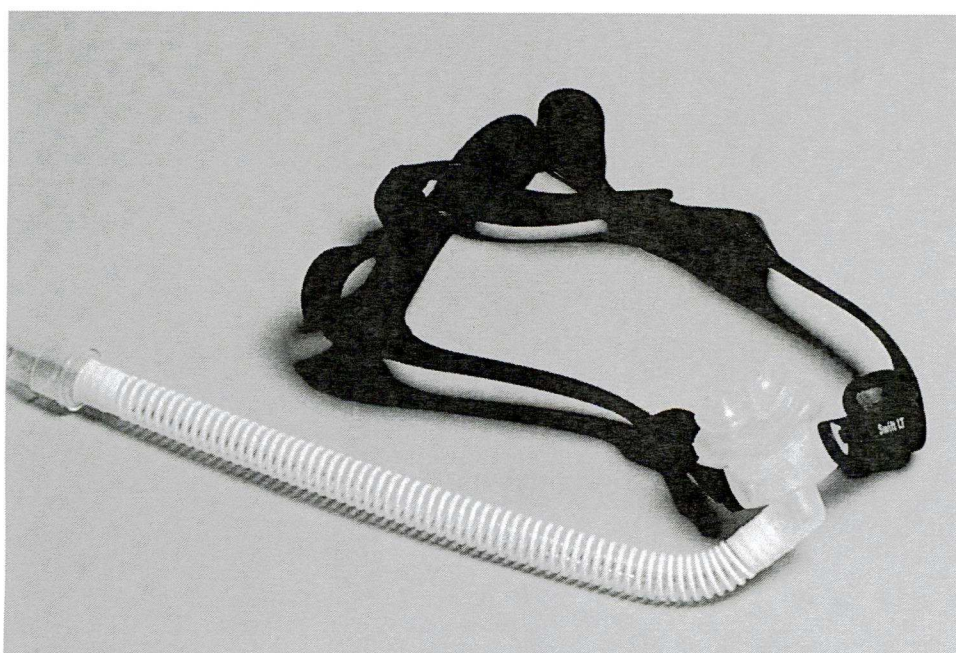
a. Full Face Mask: covering the nose and mouth



b. Total Face Mask: covering the whole face



c. Nasal Mask: covering the nose



d. Nasal Pillow: two hole going into the nostrils

*These are examples of each mask. Design and shape vary depending on suppliers

Appendix 2



‘Health benefits of Non-Invasive Ventilation in MND: the Psychosocial and Physical Impact on People with MND and their Carers’

Patient Consent Form

(Please read each statement carefully and initial each box)

- I agree to take part in this study.
 - I have read and understood the information leaflet for this study and have had the opportunity to ask about anything that I do not understand.
 - I understand that I am free to withdraw from the study at any time and this will not affect my future treatment.
 - I understand that my medical notes may be looked at by a researcher and I give permission for this.
 - I understand that participating in this study involves taking part in interviews that will be tape-recorded.

<div></div> <div>Name of Patient</div>	<div></div> <div>Date</div>	<div></div> <div>Signature</div>
<div></div> <div>Name of Researcher</div>	<div></div> <div>Date</div>	<div></div> <div>Signature</div>

Appendix 3



Patient Information Sheet

‘Health benefits of Non-Invasive Ventilation in MND: the Psychosocial and Physical Impact on People with MND and their Carers’

- Thank you for your interest in our research. This leaflet will explain the background behind our research, why we are doing this research, and how you would be involved in the research. Please read the information carefully. If you are in any way unsure or have any questions, please do not hesitate to ask.

Research Background

Motor Neurone Disease (MND) is a condition that leads to progressive muscle weakness in different areas of the body. Depending on which muscles are affected, MND can lead to a range of different symptoms, such as loss of mobility in the limbs or difficulty with speech and swallowing. Where muscle weakness progresses to the muscles of the chest, breathing problems may develop which may lead to greater breathlessness, more chest infections, and a weaker cough. It is important to identify when patients develop breathing problems in MND. Nowadays, these problems are often treated with a machine to help breathing (a ventilator). This machine is connected to a well-fitted facemask that delivers air to the patient at high pressure, enabling them to breathe more comfortably. We call this ‘Non-Invasive Ventilation’ and we now know that this can benefit people who have MND.

What is the research about?

We wish to understand what our patients (and those who care for them) think about Non-Invasive Ventilation. We would like to understand both the positive and negative aspects of life with Non-Invasive Ventilation for patients and carers. We hope that by understanding the attitudes of our patients and their carers towards Non-Invasive Ventilation, we can improve the service that we deliver to our patients. We also aim to see how opinions and attitudes towards Non-Invasive Ventilation relate to the quality of life of our patients and carers and to how patients’ lungs may be working. We are interested in your views and experiences with Non-Invasive Ventilation.

Do I have to take part?

No. It is entirely up to you to decide whether you would like to be involved in our research. There is no penalty for not taking part and if you do agree to take part you can still withdraw at any time and do not need to give a reason for doing so. Taking

part is voluntary and you will receive no payment. However, if you do wish to join the study any costs incurred will be met by the researchers.

What does my participation involve?

If you do agree to take part in the study, you will first be requested to sign a consent form.

After this, you will be asked to attend a maximum of four study visits per year for a period of up to three years (or until you no longer wish to take part in the study). The first two visits will occur at two-month intervals (one every two months) and all visits after this will take place every four months. These study visits are separate from your clinic appointments and are in addition to your routine visits to the hospital. However, if you would prefer to combine some study visits with clinic appointments (so that that they happen on the same day) we may be able to arrange this for you.

On the day of each visit, you will be invited to come to a location at University Hospital Aintree. However, we would be happy to visit you at home if you would prefer this. You have the right to choose where you would like the study visit to take place (hospital or home). We will arrange all transport for every visit and will pay for any expenses incurred as a result of your involvement in the research.

Each visit will consist of three parts:

1. Firstly, there will be an informal interview, where we will ask you about your views, opinions and experiences of MND and Non-Invasive Ventilation. This interview will be recorded on a tape recorder but your name and personal details will be kept anonymous. The interview itself will be conducted by one researcher, who will ask you around 10-12 questions. You are free to say whatever you like, as much or as little as you like, or not to answer questions if you do not feel comfortable with them. We can assure you that all that you say during the interview will be heard only by three other senior members of the research group (Dr Angus, Professor Young, and Dr Thornton).
2. After a short break, we will move onto the second part of the study where we will see what your lung capacity is like. We will perform some simple breathing tests on your lungs. You may already be familiar with these tests, as they are all tests that you would have done previously during routine visits to the chest or neurology clinic. If you are using a ventilator, we would also like to take some information from it. This will all be done by a trained healthcare professional from the hospital. You will do these tests once in every study visit.
3. In the third and final part of the visit, we will go through a number of questionnaires together. These aim to find out more about you and to explore different areas of life with MND, including your general health, what your breathing is like, how you are feeling and the impact of MND on your daily living.

Additionally, we would like to measure the levels of oxygen in your blood overnight, around the time of each visit. To do this, we will provide you with a small device (an 'oximeter') that clips onto your fingertip and will ask you to wear this device overnight in your own home. This device is designed to be comfortable for you to wear and not to interfere with your normal sleep routine. You will be asked to wear this for one night around the time of each of your study visits (up to a maximum of four times per year). This can be done on the night of your study visit or on another night around the time of your visit that is more convenient to you.

After each visit we will arrange transport to take you home (covering all costs incurred). We estimate that each study visit will take 2-3 hours. You will be invited to take as many breaks as you require and refreshments will be available at all times for yourself and those who accompany you.

Will my treatment be affected by my participation?

No, not in anyway. Whether you choose to take part or not, your care in hospital will not be affected now or at any time in the future.

Will a doctor be available during the visit?

Yes. Two of the senior researchers are medical doctors, one of whom will always be available if required. If we visit you at home, a trained medical or healthcare professional will always accompany the researcher.

Will my taking part be kept confidential?

Yes. Your participation is strictly confidential. If you consent to take part in the research, only the named researchers will have access to your medical records. Your name will not be disclosed to anyone outside of the research team in the hospital nor will it be possible to identify you in anyway in any written reports. All information will be stored safely and securely.

What are the benefits of taking part?

This research will not directly influence the care and services that you will receive, however, we hope that the information that you give to us will help us to understand MND and Non-Invasive Ventilation better and to improve services for patients and their families in the future. We also hope that being able to talk to us about your experiences may be useful to you.

What are the risks of taking part?

We aim to understand your views on the impact of breathing difficulties in MND and the treatments we offer. We fully understand and appreciate that discussing certain things related to this may be sensitive or upsetting. We would like to reassure you that you do not have to answer any question or talk about anything that you do not feel comfortable with. We would also stress that medical and nursing support will be available throughout. If you feel that you need extra help or advice, we can give you information about support services that are available to you.

Can I withdraw from the study?

Yes. You are free to withdraw from the study at any time and do not need to provide any reason for doing so. This will not affect your treatment in any way, now or in the future.

Who is doing the study?

The senior researchers are doctors from the Respiratory Department at University Hospital Aintree (Dr Angus), the Neurology Department (Professor Young) at the Walton Centre, and from the Psychology Department at the University of Liverpool (Dr Thornton). Interviews and questionnaires will be conducted by a trained researcher (Hikari Ando).

Who has reviewed the study?

This study has been favourably reviewed by Liverpool Paediatric Research Ethics Committee.

What if something goes wrong?

If you have any questions or concerns at any stage of your involvement in this research project, please feel free to discuss these with the research team. We will do our best to resolve any problems quickly. If you are still unhappy and wish to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service (NHS) complaints mechanisms are available to you. Further details and advice can be found on the NHS website www.nhs.uk or by phoning NHS Direct on 0845 4647. You may also discuss the complaints process with the Patient Advice and Liaison Service (PALS) at the Walton centre by calling 0151 529 6100.

We do not foresee any risk of harm to you during this study. However, if you are harmed in any way by taking part in this research project you should be aware that there are no special compensation arrangements. If you are harmed due to someone else's negligence, you may have grounds for legal action but you may have to pay for this yourself.

Where can I get more information from?

If you have any further questions or would like some more information, please feel free to contact Hikari Ando by telephone (0774 7797 741) or by email (hikari.ando@nhs.net). Hikari will be happy to discuss any concerns and to answer your questions.

Thank you for taking the time to read this information sheet.

If you agree to take part, you will be given a copy of this document and a signed consent form to keep. If you have any questions please feel free to contact Hikari.

APPENDIX 4

Interview Schedule

1. MND

- What were your thoughts when you were told that you had MND?
- Did you want to find out more about MND and if so how did you do this?

2. Pre-NIV

- When did you find out people with MND can have problems with breathing and their chest? How did you find out this?
- When help was offered for your breathing what were your thoughts?
- Do you feel you were told enough about the helps that you could have for this? What other things would have been useful at the time to help you decide what to do?

3. Post-NIV

- What did you think when you were shown and started on the ventilator?
- What has it been like to use the ventilator (prompt good and bad)?
- How has this gone with your carers?
- Would you go for this again now you know what it is like?
- What would you tell other people with MND about this treatment?
- What are your thoughts about the future?
- If you were to get a concurrent illness and your chest became worse (you were seriously ill), how would you like to be cared for? Would you want to stay on the ventilator?

4. General questions at follow up interviews

- Has there been any change since I last saw you? If so how does the change affect you in day-to-day life?

5. Healthcare professional

- Did anything helpful or unhelpful happen that we should know about?

Catherine

<p>Official diagnosis</p>	<p>OK, so perhaps we could start by talking a little bit about when you received your diagnosis – now, when was it that you were actually diagnosed with motor neurone disease?</p>
<p>Not able to officially diagnose</p>	<p>Well, I was diagnosed officially in April, but I was told basically in February of last year that I had MND. It was [doctor4] who confirmed it for me in the April.</p>
<p>Suspicion created because of not being official</p>	<p>But you were told unofficially before that?</p> <p>Yes, I was told that it was MND but they couldn't write that officially on my records yet, but it was that anyway. [Long pause] But it being unofficial sort of thing, well, made me feel a bit suspicious about it all really [laughs], a bit hopeful, like maybe it isn't if they can't say for sure, but then [doctor4] in the April was able to make it all official and it's just gone along that path since then.</p>
<p>MND path</p>	<p>But until it was made official you held out that bit of hope that it wasn't MND you think?</p> <p>Oh yes. How could you not? Yeah, I think you always hold out that bit of hope until they tell you it is actually MND - officially. And, um, yeah.</p>
<p>Holding onto hope before official diagnosis</p> <p>Official diagnosis</p>	<p>And when you were first told that you had</p>

	<p>tor neurone disease – what was your initial ction to the news?</p>
<p>Diagnosis devastating</p>	<p>Oh it was devastating really, I don't think I can say it any other way than that. Yeah, just so devastating. I was a bit, inside, I was a bit overwhelmed, you know it was that sort of overwhelming feeling of it and shocking as well; it was a shock because you just don't think something like that will ever happen to you, you just don't think it. Why would you, I suppose? But then there it is. So, my initial reaction was just to, well, just to feel 'Why? Why did this happen?' You know, to think of what was to come with it all, to think of what was going to happen to me – all of the awful things that were going to happen – that happen to people with MND. I thought about those things for a long time; the course that the illness would take, you know. Even when I was being told what it was, those thoughts were already there in my mind.</p>
<p>Diagnosis overwhelming</p>	<p>And how much did you actually know about motor neurone disease at that time?</p>
<p>Diagnosis shocking</p>	<p>Well, I did know quite a lot about MND because I used to be a carer and I worked in a care home for many years, and some of the patients that we had in there over the years had MND. So, when she told me that that was what I had, I knew exactly what was to come. I mean I was working in a care home about twenty years ago.</p>
<p>Unexpected diagnosis</p>	<p>By saying 'I can't say any other way than that' she actually emphasise the magnitude of impact. 'So' devastating but 'a bit' overwhelmed. Devastating: 1. highly destructive or damaging 2. causing severe shock, distress, or grief. Overwhelm: bury or drown beneath a huge mass of something, especially water 2. give too much of something to 3. have a strong emotional effect on 4. defeat completely Does she mean that she was highly shocked and damaged by the news, but not destroyed? Shocking feeling but not a defeat? She explains how she was using the second person. Explain as a commonality of mentality. She is not an exception. Question the causation of MND. She didn't understand why she had MND. Was she careful with their body not to catch disease? Her question was for unfair outcome of her self observation? Unfair to get 'awful' condition? Diagnosis an unpredictable event. Diagnosis quickly linked to the prognosis she knew about. She repeats herself over the prognosis which illustrates how devastating she was and why it was devastating and overwhelming. She was devastated because she knew what was to come and also overwhelmed because of the relentless prognosis. What were actually the 'those things'? Is there any particular side of illness she had been thinking about?</p>
<p>Questions on getting MND</p>	<p>Her knowledge from her previous experience.</p>
<p>Excessive thought on prognosis</p>	<p>She expressed her absolute knowledge of the illness. Has it been the same as she expected? Is she going down the path she imagined?</p>
<p>Concern over prognosis already exist when diagnosed</p>	
<p>Knowledge from previous job</p>	
<p>Clear path of the illness from her experience</p>	

<p>Not expected diagnosis Her symptoms different from her MND knowledge Her symptoms as evidence of MND No idea of getting MND</p>	<p>Right -</p> <p>So, yes, I knew very much what was ahead of me, and I mean, it's funny, I don't think I'd really suspected MND from my symptoms early on, but it just goes to show you – I'd seen the effects of the illness in these people but not where it all started from, so for me I didn't see it in myself right away. Didn't even think it might be that really.</p> <p>And what symptoms had you noticed in yourself that led up to your diagnosis?</p> <p>At first it was just falling over, and like, I thought I had drop foot. I was falling over a lot more and plus I had arthritis in my right knee so I got myself a walking stick to help prevent me from falling over and that did help a bit, but then I was falling over more and more, I mean, I wasn't hurting myself, you know, I was just falling over. But I got worried because I had a holiday coming up, you know, and it was a touring holiday, and I thought, 'Well, I can't go on this holiday with this falling over', and if you imagine, I mean, I was going to America. So I went to the doctor and he said go to A&E – and I'd been going to my doctor practically every week with this drop foot and he said to me 'Oh go on holiday!' and I won't tell you everything he said, but he didn't know what it was, so he examined my leg and he couldn't think of what it might be - couldn't see anything wrong with it. So I</p>	<p>Her suspicion also came from her existent experience of the patient? <i>Expressing her surprise</i> Experience as a factor hindrance or acceptance to acknowledge the illness.</p> <p><i>Delayed display of MND. Not 'right away'</i></p>
<p>Initial symptoms</p>		<p>Initial symptoms. Self explanation of her symptom: drop foot managed with her stick.</p>
<p>Planned holiday as a trigger to seek for another advice</p>		<p>Circumstance made her to go to hospital. Her symptoms were not really affecting her daily life.</p>
<p>Frequent visit to her doctor</p>		<p>Mentioning about A&E reminded her of her former experience with her doctor and she talks about the doctor rather than A&E, illustrating the stressful experience with the doctor. Negative experience with her doctor. Not being able to see anything wrong with her foot.</p>
<p>Ignorance of her doctor</p>		<p>Her description of her doctor shows her distrust of her doctor?</p>

Worrisome as a result of unhelpful consultation	<p>went to another doctor, because I was really, really worried, you know?</p> <p>Yeah –</p> <p>So I went to A&E that day and the doctor that saw me said ‘Oh, you look as if you’ve got drop foot’, he examined me and he said ‘I think you need to see someone at the neuro’ and so it started from there, they made me an appointment to go over to [hospital] and eventually I went to see [doctor4], who did say to me ‘It’s not drop foot’ and that kind of got me a bit worried, you know?</p> <p>Yeah –</p> <p>Because drop foot can be fixed. So eventually, [doctor4] confirmed that actually what I had was MND. But it was [doctor1] who told me about it a few months before or something, he said ‘I don’t know whether you’ve heard of MND, but that’s what you’ve got’ and so I had some more tests and that was that. I had MND.</p> <p>So it was a long process –</p> <p>Oh yeah, yeah, yeah it was. I mean this was going on from the June, July? You know, and I was going all the time to my own doctor, and I felt he was just fobbing me off. Because I’m sure they do have people who just go to their doctor every week and they must just think ‘Oh, hypochondriac’, you know? So, perhaps if</p>	<p>Ineffective advice from her doctor results in making her to get a second opinion.</p> <p><i>Repetition of her feeling illustrates her strong worrisome. Appeal for an agreement or approval of what she did?</i></p> <p>Her worry made her to go to A&E, but she also mentioned her worrisome after being told by [doctor4] that her problem was not drop foot.</p> <p><i>‘Eventually’: illustrates the long journey the patient made to get to the stage</i></p> <p>Misunderstanding of her condition and the consequence of the correction: worry.</p> <p>Her worrisome didn’t start when referred. Presumably because foot drop is also cause by some form of Neurological deficit.</p> <p><u>Did she just want to have a confirmation?</u></p> <p><u>‘you know?’: appeal for agreement?</u></p> <p>The difference between drop foot and MND: cure</p> <p><u>She tells that the illness was mentioned earlier, but she explained her worrisome after [doctor4] mentioned it which indicate that she did not take the first comment seriously? Or was she just hoping without official diagnosis?</u></p> <p>Repetition of her answer implies the long process.?’</p> <p><i>Strong feeling of inappropriate treatment by her GP ‘fobbing off’</i></p> <p>Her worry with symptoms made her to go to GP often but she assumes that was the reason she was not treated seriously – <u>Even though her reasoning was her assumption she is doing so to come to term with unpleasant experience with her doctor?</u></p>
Long process of diagnosis Worrisome caused by unexpected comment from the doctor		
Drop foot fixable		
MND previously mentioned		
Inappropriate treatment by her doctor Regular visit to her doctor; hypochondriac		

<p>Misunderstanding from others: drunk</p> <p>Frustrated and worried as results of mistreat from her doctor</p> <p>Repetitive visit to her doctor</p> <p>Continuous problem</p> <p>Expectation to her GP</p> <p>Doctor's responsibility became her responsibility</p> <p>The dealing with her doctor led to the diagnosis</p> <p>Not being listened generated anger</p> <p>Know your own body</p> <p>Think back about her doctor makes her upset</p>	<p>I hadn't gone as often [laughs]. But I was worried, you know, especially with falling over. People think you're drunk [laughs].</p> <p>Well, that must have been very worrying for you. And frustrating that it was so hard for you to get through to your own doctor?</p> <p>Yeah, yeah, that's exactly how I felt – very, very frustrated and just so worried. It is frustrating when people don't listen to you. But I thought, with me going backwards and forwards to him, I was still falling over and having the drop foot – as I thought – he still should have referred me earlier to the hospital. But he didn't. And it must have been the January, maybe the January, because I was going away, um, in the March, I know it was only a few weeks away and I was getting really worried. And so, I knew I had to do something, I couldn't possibly go on holiday, and that's how it all turned out. All that going on and he wouldn't listen.</p> <p>As you look back at the situation now how do you feel?</p> <p>Very angry really [laughs]; just very angry that I wasn't listened to, because you know your own body, don't you? So, yeah, it does upset me now to think back about that time and that doctor not listening to me.</p> <p>And now, you mentioned that you had that background of caring for people with MND,</p>	<p>She is judged as drunk. Because of falling over</p> <p>Consequent feeling of mistreat. <i>Strong feeling 'very' and frustration.</i> Inappropriate response creates worrisome. External influence on mentality.</p> <p><u>Repetitive appeal to her GP as her seriousness of problem.</u></p> <p>Continuous problem with falling over</p> <p>Expectation towards the GP. <i>'Still' he still should have refer her even he may not have realised the seriousness of the illness</i></p> <p>Decision to be made as a consequence of inappropriate response from her doctor: <u>the patient needed to do something as her doctor wouldn't do anything although he was supposed to so it became her responsibility.</u> The diagnosis was brought about in an unusual way where the doctor would not listen, which is a total contrast of <u>how it should be.</u></p> <p>Why did she laugh? Not being listened</p> <p>Her observation of herself was most reliable account? That's also why she should have been listened to. <u>Appeal to agreement is used in a way to convince the interviewer.</u> <i>She is expecting a positive answer.</i> Effect of the manner of response. Being listened important. Still upset her to think back. Did it also upset her? Or did it just frustrated her and caused worrisome then?</p>
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so you had some knowledge of the illness, but when you got that diagnosis, did you want to get more information?

Yeah, yeah I did. I knew that well, I know what I know about it but I didn't know *everything* of course, because I was only a care assistant, but I mean, at the time, I was [laughs] I was hoping it was a mistake. But as it's turned out it's not.

So even after the diagnosis you hoped it was a mistake?

Yeah [laughs]. But I suppose that's a little bit of human nature coming out isn't it? You just hope it's wrong and you're going to be ok. But it was just difficult to accept it at first and I really, well, I *wanted* them to be wrong. But maybe I knew in my heart of hearts that they weren't.

Yeah?

And then of course the MND gets worse in you and then you really can't deny it to yourself anymore. So actually the MND makes you accept it because it's all of a sudden there and real – it's really in your face very quickly [laughs]. And it's when those sort of symptoms kick in, like your legs get worse and you're in a wheelchair and that, I mean you need to know about it don't you? I would imagine it's very difficult to get by with MND if you didn't look into these things. So, actually, although I did know a lot about the

Active attitude towards information

Hope for diagnosis as a mistake

Hope as a human nature

Difficult to accept diagnosis

Knew in her heart of hearts

MND convince her of the illness

Attempt to deny MND as another being which grows and reveals

Empowering of MND

Information to get by with MND

Active attitude towards information. Eager to find out about everything and as reveals after 'I mean' it was more to prove the diagnosis was wrong. Laugh as the patient thinks it was unrealistic? I mean: the real reason.

'at the time' finished business. No more unrealistic hope.
'as it's turned out' in her symptoms?

Human nature seeks for better environment and try to avoid any danger? Evolutionary instinct? Instinct as a human being Even after it's confirmed we still try to hold onto the little hope. *'going to be ok': no threat to her life?*

Difficult to accept

Her hearts is a place all the truth is unconsciously acknowledged?

Not influenced by hope or unstable human feeling, but remain fact-oriented-process

MND convince her of the illness. *MND as another existence in her body: not unified.* MND described as almost another existence in her which grows. MND gradually dominates in the patient. But latent characteristic of illness can be denied at the beginning 'actually': the illness is the factor which makes her acknowledge the illness not the diagnosis. It's a rapid gradual empowering of MND but consciousness rejects to acknowledge the change which will be eventually acknowledged and then it appears to be a sudden change.

Legs get worse - wheelchair

MND describes by third person. MND first illustrates as a foreign element in her body whose existence was denied, but patient then

Previous knowledge on the effects of MND Active information seeking attitude Attempt to get clear picture of MND	effects of the MND, even I had to look things up and even I from day one really wanted to know more about it – I didn't feel I knew enough about it. I wanted to know exactly what I could expect. I wanted to know the score exactly, you know?	acknowledged the impossibility of omitting or denying thus she needs to live 'with' MND. It's important to know the nature of MND to live with. Emphasis on her knowledge on the illness. Active information seeking attitude. Her attitude seems to indicate her characteristic as determine and active problem solving nature. Black or white? 'exactly' not how it may be or roughly. <i>Appealing for understanding or agreement.</i> Information seeking for preparation.
Information for preparation Previously thought MND manageable?	And why do you think you wanted to know that? I wanted to be prepared really. Didn't want it sneaking up on me I suppose. Yeah, I thought if I knew what was to come, well, it would make it easier for us to get things ready and just prepare ourselves for it all, get things in place. And [long pause], yes, I guess, um, partly as well you're looking for loopholes [laughs].	Didn't want it sneaking up on me All the problems were considered solvable or manageable? Excessive thought Or rather hesitant to share it with the interview as she thinks its unrealistic which also makes sense why she laughed (maybe the latter)? Loopholes.
Information for loopholes	Oh right, what kind of loopholes were you looking for? Oh, um, well, maybe at first you sort of want to prove it all wrong, but as I say the illness itself puts paid to that sharpish. No, I think just like, not a cure exactly, but just like can I stop it getting worse quicker, you know like, what should I be doing to try and make it not as bad. 'Cause if you can't stop it getting worse you at least want to put it off for as long as possible.	Sounds like she is trying to understand her action retrospectively. Did she not know why she was doing it then? Effort to understand one's conduct or thinking process. 'if you can't stop it getting worse you at least want to put it off for as long as possible'
Information to slow things down MND: stream train MND stoppable?	Yeah - Oh but it's a bit like a steam train isn't	MND: slow to start

Excessive thoughts MND: controllable/ not controllable Control by a way of getting information	<p>it? You know, takes a bit to get going but then once it picks up pace, you're pretty hard pressed to stop the damn thing [laughs]. I don't know, I suppose [exhales] sometimes it seems a bit out of your control, but in the beginning at least, you know there was a lot to be said for knowing what was what. So, um, oh was that the question? I've forgotten now [laughs], you said about finding out about it did you?</p> <p>I did, about wanting more information after the diagnosis.</p> <p>Oh yeah, sorry that's me going off on one [laughs].</p> <p>Oh no, not at all, you feel free to say whatever's on your mind about these things.</p> <p>Oh yes, well, information, as I said really. Yes, I did want to know more about the MND.</p> <p>And your daughters as well, did they want to get more information about the illness?</p> <p>No, no they didn't actually. Well, [daughter1] didn't, she would just prefer to live day-by-day rather than knowing what's going to happen – she worries see about it all. Whereas [daughter2] looked it up on the internet and all this stuff. But to be honest, now, I don't think she's looking anymore – you go looking because you think there might be a bit of hope or something, I've already said that</p>	<p>Metaphorical account: 'steam train' illustrates its rapid speed with burning coil which would not stop until they are all burnt. She is expressing the nature of MND which demands her a lot to control. Does her laugh implies her feeling of hopelessness? <i>Clueless or a feeling of lost: 'I don't know'</i>. She is trying to understand and explains her position. Reality is hard to admit [exhales] and it is getting worse as time goes on.</p> <p>There was a sense of control at the beginning by obtaining information? but then diminishing. 'at least' only in the beginning</p>
Active attitude towards information seeking		Active attitude towards information seeking.
One daughter prefers day-by-day approach avoidance because she worries Change in other daughter's information seeking attitude No hope from information		<p>Daughter reaction towards MND information One daughter's preference to life day-by-day</p> <p>Avoidance because of worrisome</p> <p>Change in daughter's information seeking</p>

<p>Nature of information</p> <p>Impact of the nature of information</p> <p>Pointless preparation</p> <p>Reluctant to prepare : horrible</p> <p>No more information and MND</p> <p>Being fed up with information and MND</p> <p>Passive towards</p>	<p>I think, have I?</p> <p>No, no, that's fine; you think there may be hope so you look for information...</p> <p>Well, I think it is something to do with it, but you soon realise, well, you see quick enough there isn't nothing like that and you soon stop looking for whatever it is you think <i>might</i> be out there [laughs]. But there's not a lot out there that makes you want to keep searching, I suppose. You may as well just take it as it comes to you – knowing about it isn't going to make it any easier. There comes a point I reckon where even like this being prepared is pointless – it's so horrible that you don't want to be prepared for it. And our [daughter2], she's learnt enough now and doesn't want to know any more, you know?</p> <p>Yeah -</p> <p>So, that's just where we've come to.</p> <p>Well, that's interesting, so how much information you want about things, that changes you think, as the illness progresses?</p> <p>Oh yes, I would say that's true. Yeah, I would say you get to a point and you just feel like 'Oh no more, no more information, no more MND, I'm sick of it – leave well alone'. You just start to want to see what happens rather than knowing what's gonna happen and then just</p>	<p>No hope from information</p> <p>Motivation for information seeking: hope.</p> <p>Hope and information seeking is probably related.</p> <p>The patient generalising the motives by using second person 'you'. Maybe she is talking again about the characteristic of human nature to look out for positive, but also a instinct to notice the reality?</p> <p>The nature of information doesn't make you want to keep searching. <i>She is personalising the information to put off from looking for info.</i></p> <p>The nature of information affects patient's attitude towards information. The initial motivation discouraged by the nature of the information.</p> <p><i>Pointless: having little or no sense, or no purpose. The patient is focusing on her lack of motivation rather than whether there is something she can prepare.</i></p> <p>How about herself? Was she just explaining about her daughter?</p> <p><i>'Learn': awareness of reality which was not available before.</i></p> <p>Expressing understanding towards daughter's altered information seeking attitude.</p> <p>'We' includes both her daughter and herself.</p> <p>No more information, no more MND</p> <p>Being fed up with information as well as MND</p> <p>Sense of surrounded by MND and information?</p>
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information and preparation Generalisation	<p>waiting for it to happen. No one wants to wait for bad things to happen, do they? I think that's a lot to do with it, you know, with looking out for what's what.</p> <p>Ok, well, if we move a little bit to talk about a more specific aspect of the illness – the changes that can occur with your breathing.</p> <p>Yeah.</p> <p>Now, at what point did you learn that your breathing might be affected by the MND?</p> <p>Well, I knew that from years ago when there was one gentleman we was looking after that had MND and I knew his breathing was quite badly affected by it, but I didn't know really the extent that it would be affected by it. But sadly, I knew in advance of all this, you know, what it could do to your breathing muscles.</p> <p>Right, and how did you feel about that?</p> <p>About it affecting the breathing?</p> <p>Yeah -</p> <p>That was quite a frightening thing for me. It's enough what it can do anyway, but the breathing especially is, um, yes is frightening to me [long pause] because I remembered him this chap, you know, I remember his, um, he was really breathless almost all of the time in the end, towards the end, and fighting, you know, really fighting to breathe</p>	<p>Active attitude becomes passive towards information. No preparation</p> <p><i>Justifying her position by human nature: 'no one' Appeal for agreement. Expect the agreement.</i></p> <p>Impact of information</p> <p><i>She did not want to know about the breathing problem? 'sadly'</i></p> <p><u>It sounds strange that she said sadly as she earlier expressed her willingness to gather information about the illness. Maybe because it was quite badly affected? Information not helpful, but just overwhelming?</u></p> <p>Breathing thing as quite frightening</p> <p>Breathing problem as the significant element compared to the rest.</p> <p>Excessive thoughts</p> <p>Retrospective account of the man</p> <p><u>End of life and breathlessness is associated in patients because of</u></p>
<p>Knowledge on breathing problem from her old job</p> <p>No definite knowledge of the course of breathing</p> <p>Preference of not knowing breathing problem</p> <p>Breathing especially frightening about MND</p> <p>Excessive thoughts</p> <p>Observation of man fighting to breathe</p>		

<p>Gentleman hanging on to life by breathing</p> <p>Status of life is important</p> <p>Doesn't want to fight for breath and cling on to life</p>	<p>sometimes actually – hanging on to life really I suppose,. You know, despite all how he was the rest of him. That surprised me actually. So, um, what I thought was that I didn't want to end up like that gentleman in the home, fighting for breath and clinging on to life like that. He was in my mind a bit.</p> <p>Do you think this all would have been easier for you if you hadn't known so much about MND – hadn't seen these things for yourself?</p> <p>Yeah, I think once you've been in that profession and like I'd seen a man go through the whole illness - that affects you. I think that's what's made it so hard for me, I keep thinking of what's to come, and I think anything is easier when you don't know what's coming, rather than knowing what's coming and waiting for it to happen.</p> <p>Yeah, now earlier you spoke about wanting to be prepared and to get more information, but you think it can also be difficult to know what's going to come?</p> <p>Yes [long pause]. I suppose I've gone against myself a bit there [laughs], but, well, it's hard to explain [long pause]. You do want to know, you do want to sort of find out about it, but when you know things like knowing about the breathing, well that's not very nice to know. I suppose you want to know, but when you do, you maybe wish you didn't but you</p>	<p>her observation of the patient.</p> <p>Hanging onto life by breathing</p> <p>Gentleman hanging onto life regardless of the rest of him</p> <p>Surprised with the gentleman</p> <p><u>She doesn't want to hanging onto life if she is just fighting to breathe, but nothing rest</u></p> <p><u>Sense of dignity? Independence?</u></p>
<p>General impact of experience</p> <p>Negative impact of information</p> <p>Ignorance is better than knowing what to come</p> <p>Anticipation of future deterioration</p>		<p><i>Generalising her experience to everyone. Then talked about her case. Persuading the interviewer?</i></p> <p>Information negatively affect her: 'keep thinking of what's to come' <u>So, impact of information is too overwelming to just prepare?</u></p> <p><i>'Anything is easier' exaggerating? Especially because it seems to go against her previous approach to MND</i></p> <p>Anticipating future deterioration</p>
<p>Excessive thought</p> <p>Agony with information on MND</p> <p>Wanting to know but regret to find out</p>		<p>Excessive thoughts</p> <p>Agony with information on MND</p> <p><u>It's probably that she wants to get the info as long as it is manageable or if there is anything she can do to moderate the problem. Breathing is a good example which she only observed the helpless status of the man.</u></p> <p>The agony is caused because of the nature of the information.</p>

Victim of her previous job	<p>can't go back on it. But then it was never my choice to find out about the breathing, I just knew that from the home, but maybe I would have found that out anyway when I looked into it in the beginning.</p> <p>Do you feel it's the nature of the information then – what there actually is out there to know?</p> <p>Yeah, it's pretty, um, well it's not nice is it? If it were more, um, a bit better or hopeful or a bit more tolerable, but it's not, all of the MND is just all of the worst things you can imagine really, and I say that from the experience of working and seeing these things; I say that from my own experience of it through the home, not just what I've got in my experience of having it now. But [long pause] the breathing, yes, that is a cruel thing of it from what I saw.</p> <p>Yeah –</p> <p>I've always thought it was a bit of a curious thing breathing really, you know, you don't think about it, do you? But actually, isn't it the <i>most</i> important thing? And it's the one thing we take for granted – stupidly, actually. You're not nothing without your breathing but you just don't even think about it [laughs]. Yeah, funny that really – yes, it is, it's funny.</p> <p>Well, perhaps if we could talk about your</p>	<p><i>Her use of second person may indicate her persuasion.</i></p> <p><i>She illustrates herself as a victim of her pervious job 'it was never my choice',</i></p> <p>yet she would probably find out is anyway as she mentions.</p> <p>Negative nature of information</p> <p><u>She describes there is little hope. Only a little bit of something to hold on to or hope for is not available. There is nothing to make it better.</u></p> <p><i>Her argument supported by two aspects to make the point strong.</i></p> <p>Breathing is cruel thing</p> <p><u>Always: since when? Since her experience with a man in a home? She assumes a general disinterest on the nature of breathing by using second person. She expect interview to agree with her 'do you?' . Breathing: curious thing</u></p> <p><u>Contemplation on life sustained by breathing</u></p> <p><u>'We' inclusive, as a human being general? Human being strives for positive information to remain hopeful, but also stupid at the same time as we don't acknowledge the most important thing in life? Are we focusing on a irrelevant thing? We seek for hope to keep going but forget what's the fundamental thing to keep our life?</u></p> <p><u>Life doesn't exist without breathing Interesting point considering the account of the Bible where Adam became alive only after</u></p>
Ger arguments supported by two aspects		
Breathing is cruel thing		
Breathing is curious thing		
Usually ignored of the significance		
No life without breathing		

<p>Breathing is quite good Causation of breathlessness: doing too much, upset No problem cause by breathing Not upset with breathing Comfortable in bed</p> <p>Previous breathlessness was due to depression</p> <p>Breathless problem solved by anti-depressant</p> <p>Anxiety to be blamed for her breathlessness</p> <p>No realisation of being depressed Effective anti-depressant</p>	<p>own breathing, I know that you were recently referred to have that checked – how do you feel that situation at the moment?</p> <p>I mean actually my own breathing is quite good; I do get slightly breathless if I have to do too much, and if I get upset, but actually it doesn't cause me any problems or any worry or any kind of, um, it doesn't upset me. I mean, I'm usually just sat here during the day or I'm in bed and it doesn't cause me any problems here or in bed, I'm quite comfortable in bed. I mean, the reason I think they wanted to check my breathing was because I was having this little bit of breathlessness – but since [doctor4] has started me on these anti-depressants, actually it's almost completely gone.</p> <p>Right –</p> <p>So I put that breathlessness down to anxiety. You know, I mean, I didn't think I was depressed, but see I was whinging for nothing and crying for nothing and my daughter kept saying 'Oh, I'm sure it's depression mum' but I actually felt ok. And [doctor4] put me on anti-depressants and I felt better almost immediately. I mean, she did say it would take about five weeks before we would see the effects, but I've noticed the difference in myself as soon as I starting taking them. I was crying at the drop of a hat, you know.</p> <p>Right, but in yourself you felt ok?</p>
<p>God blow into his nose. But then if one is just breathing that's the most important thing to be alive? Like the gentleman? But she doesn't want to be only breathing. Breathing is the most important thing, but not only aspect of life? Funny: breathing most important, but not acknowledged</p> <p>Breathing is quite good . Although she admit that she gets breathless, but that does not mean her breathing is bad. Her temporary condition and her illness stage are separate thing Her experience does not define her status? Why she mentions being upset as an result of getting breathless rather than worrisome? Her daily life does not contain any factor to make her breathless. Moreover, she feels comfortable.</p> <p>Although she was ambiguous about the reason for the test she appears to be convinced that her emotion status affects her breathing as seen in her 2nd reason of making her breathless. <i>Actually- 1. used when expressing a contradictory or unexpected opinion or correcting someone. 2. used to add information to previous statement.</i></p> <p>Anxiety to be blamed for her breathlessness</p> <p>She admits her anxious status only after she could see the change: she needs an evidence to be convinced? Like diagnosis with MND? Her feeling as sometimes deceitful? Effective medication Change as an evidence.</p>	

Retrospective account on her previous depressed status She felt ok	Oh yes, I felt I was ok but I was whinging on all the time and so I must actually have been depressed but not really noticed. But in myself I felt that I was ok, I felt really rather alright. And you mentioned some anxiety – Yeah. Is there anything in particular that causes you to feel anxious? No, no I mean, I didn't think I was anxious – but they told me I was and at the back of my mind I must have been. I can't think of anything that actually causes me to feel anxious, but at the back of my mind there could be something, you know, sort of an undercurrent, you know? Yeah – But I don't know. It's a funny one really, but maybe I'm anxious and I'm depressed without even realising it. That seems to have been what they've said, you know, they've told me that that's how I am. But you've not felt that way yourself? No, no I wouldn't have thought I was if they hadn't told me I was. So, they got me on these anti-depressants and they seem to have helped with the problems.	Retrospective account on her previous depressed status She repeatedly emphasises that she felt she was ok. Feeling of her condition rather than objective examination
Objective self and subjective self Back of my mind as a different realm	No, no I mean, I didn't think I was anxious – but they told me I was and at the back of my mind I must have been. I can't think of anything that actually causes me to feel anxious, but at the back of my mind there could be something, you know, sort of an undercurrent, you know?	Objective self and subjective self At the back of my mind: where only fact matters. Unconscious realm that also deals with matter which is not captured by conscious? So, her mind agrees with external opinion which suggest its detached nature from her feeling-self? She appeals for interviewer's agreement or checks if she was understood.
Funny Not understanding her psychological condition thoroughly	Funny: being anxious/depressed without noticing Consequence of the former experience: Possibility of not understanding her psychological condition thoroughly. This argument seems to imply almost that the self is not always sensitive to all the things going on in the self and fail to acknowledge some of them. Sometimes outsiders are more sensitive?	Funny: being anxious/depressed without noticing Consequence of the former experience: Possibility of not understanding her psychological condition thoroughly. This argument seems to imply almost that the self is not always sensitive to all the things going on in the self and fail to acknowledge some of them. Sometimes outsiders are more sensitive?
Elements which made her think she was depressed	She immediately accept the idea of being depressed? Anti-depressants helped her to observe herself. So, she accepted that she may be depressed when they told her or she acknowledged it when she could see the effective of medication? Gradual acknowledgment – surrounding and medication?	She immediately accept the idea of being depressed? Anti-depressants helped her to observe herself. So, she accepted that she may be depressed when they told her or she acknowledged it when she could see the effective of medication? Gradual acknowledgment – surrounding and medication?

<p>Change after medication: more positive</p> <p>Former reasoning for crying</p> <p>Optimistic view on her breathing</p> <p>Anxiety made her breathless</p>	<p>You feel the anti-depressants have helped – in what way then, if you felt ok before, how would you say they’ve helped?</p> <p>Oh being more positive, yeah, yeah. As I say, because I’m not crying for no reason at the moment. I’d just been crying for no reason before – just feeling sorry for myself is what I put it down to [laughs].</p> <p>Yeah?</p> <p>But the anti-depressants have helped with that and I think now as well you see that my breathing will be absolutely ok again - because I’m not anxious anymore.</p> <p>But you’d noticed you were getting breathless before – because of the anxiety?</p> <p>Apparently so.</p> <p>But you didn’t feel anxious yourself?</p> <p>Not really.</p> <p>How is your breathing now, since you started taking the anti-depressants?</p> <p>I think it is fine now actually. I haven’t had any more actually being breathless since they started me on them, so it really must just have been my anxiety. You know, I would say actually since I started taking the anti-depressants my breathing’s also improved a lot.</p>	<p>Change after medication: more positive</p> <p>Former self reasoning</p> <p><u>Why did she laugh?</u> Because she doesn’t think it was a convincing reason? Or she feels embarrassing with her reasoning?</p> <p><i>Persuasion: ‘you see’ with reason</i></p> <p>Optimistic view on her breathing with the medication.</p> <p>Confidence ‘absolutely ok’</p> <p>Self reasoning</p> <p><i>Expressing corrected symptom: ‘actually’</i></p> <p><i>Emphasising no more problem with breathing.</i></p> <p>Case solved</p> <p>Her improved breathing further convicts anxiety being the reason.</p> <p><i>Mentioning her improved status</i></p>
<p>Change after medication: more positive</p> <p>Former reasoning for crying</p> <p>Optimistic view on her breathing</p> <p>Anxiety made her breathless</p> <p>No more breathlessness</p> <p>Anxiety to be blamed for</p>		

Improved breathing	<p>And I know [doctor4] has referred you to have some tests done on your breathing - now how do you feel about that?</p> <p>Oh, I don't mind that. I don't fancy the breathing thing though, you know, I don't fancy that - the whatever it was you said before.</p> <p>You don't fancy the ventilator?</p> <p>No.</p> <p>Oh right, now, is there any aspect of that in particular that you don't like the sound of?</p> <p>It's just having the mask on I think, yeah, mainly the mask. I don't think I like the sound of that at all really.</p> <p>And why's that?</p> <p>Oh it just seems a bit; well it's scary having something like that on your face I think. And I'd imagine it's quite claustrophobic as well; yeah, just having to wear that thing - doesn't sound very nice to me.</p> <p>And it was [doctor4] who explained to you about the machine, is that right?</p> <p>Yeah, oh yeah, she just said it was like a thing that will help you, that blows air into your face to help you breathe. And it's that really, having something on your face, you know, this mask business, and also the air blowing into your face, and at</p>	<p>No objection with breathing assessment</p> <p>She doesn't fancy 'breathing thing'</p> <p>She expresses her dislike of having the mask on</p> <p>Not a specific reason of why she doesn't like the sound of mask.</p> <p>Not definite imaginative reason of not liking the mask.</p> <p>Mask is scary. <u>Why scary? Mask would hinder her breathing? It would work opposite from what it should be doing? It would do some damage rather than good? Presumed uncomfortable characteristic of mask, claustrophobic</u></p> <p>She doesn't like the idea of having something on her face.</p> <p>Mask business</p> <p><i>'Regular intervals' just like she does by herself</i></p> <p><u>Regular intervals to help her breathe. She seems to have a problem with how NIV functions or how it helps her. Considering</u></p>
<p>no objection with breathing assessment</p> <p>not fancy the breathing thing</p> <p>Not liking having the mask on</p> <p>Don't like the sound of having mask on</p> <p>Scary to have something on the face</p> <p>Imaginative claustrophobic mask</p> <p>Doesn't sound very nice: having to wear</p> <p>Having something on your face</p> <p>Regular interval of air blow</p>		

<p>Permanent nature of NIV use</p> <p>NIV would become a must-have item</p> <p>Uncertainty of her ability to deal</p>	<p>regular intervals, you know?</p> <p>Yeah -</p> <p>Yeah, I just don't think I would like that, because as well, it's not just for a little bit, it's not like oh you're ill and you need to use this mask for a little while, you know, it would be for you to help you to breathe for the rest of your days then. It would end up being a permanent thing of you having to use it. I don't think I want that really. I'm not sure I would be able to just deal with that.</p> <p>Is it something that you feel you'd be willing to try or - ?</p> <p>Well, I will try it for them, but whether or not I'd be willing to accept it or not, I don't know [laughs]. I don't know, I mean I don't know much about them, other than what I do know I don't much like the sound of.</p> <p>Is it something that you'd like to know more about?</p> <p>Well, not yet, but maybe at a later stage. As I say, my breathing is really a lot better now, actually, I've no complaints at all. But I feel generally better, so it must just have been a bit of depression.</p> <p>Yeah -</p> <p>And that could have been affecting my breathing, you know?</p>	<p>the way she understands 'breathe' it is the machine doing a job to keep her alive? <u>Appeals for agreement on what she argues about NIV disapprove NIV</u></p> <p><u>The idea of permanent use of NIV. The impression of NIV</u></p> <p><u>NIV permanent must-have life sustainers</u></p> <p><u>NIV not as a treatment to cure</u></p> <p><u>NIV not a cure but to depend on, not even to live with.</u></p> <p><u>She even questions her capability of deal with NIV or status of needing NIV?. What would be so difficult? Her dependent on NIV. independence?</u></p> <p><u>Trial for medical people not for herself. Sense of being in charge of her decision?</u></p> <p><u>She wants to know about things before she decides; assessing the issue before making decision</u></p> <p><u>She doesn't like the sound as far as she knows, but there are not a definite answer.</u></p>	<p>Not yet. Maybe later stage.</p> <p>her breathing a 'lot better'. No concern about her breathing.</p> <p>General good condition</p> <p>'a bit of depression' the problem with depression as a bit.</p> <p>Reasoning of breathlessness but with uncertainty</p>
<p>NIV information not yet as her breathing is better</p> <p>No complain on her breathing</p> <p>A bit of depression caused breathlessness</p>			

<p>Sense of premature assessment of her breathing</p> <p>Future plausible interest in NIV information</p> <p>Perceived recovered breathing</p>	<p>Yeah?</p> <p>But I do feel generally better.</p> <p>So actually, you think maybe talk of these things is a little premature?</p> <p>I do really, yes, it is really. I mean I should think they'll want maybe to talk about these things if the time comes that I do start to need help with my breathing and I probably will want to know a bit more about them then. Not now though, because it seems like my breathing is really back on track now.</p> <p>Right, so you'd be willing to find out more about the ventilator, and possibly to try one, but not yet, because you don't feel you need that yet – you'd rather find out more when you need it?</p> <p>I think so; I don't feel that I need to know much else yet. I'll just forget it if they tell me now probably anyway [laughs].</p> <p>Ok, well in that case how do you feel about being referred and having your breathing tested?</p> <p>Well, fine really because I know that it's ok really. I think that was just because of the earlier things with my breathing, with being anxious. But I'm improved since then, so I suppose it might not be exactly</p>	<p>Her confident of depression affecting her breathing seems to have lost its degree a bit. Why? She can't be hundred percent sure that it was only from her depression? Especially because she knows how MND can affect her breathing?</p> <p><i>Should: indicating the consequence of an imagined event.</i></p> <p>Her feeling of premature process with her breathing.</p> <p>Imaginative, but active approach to NIV</p> <p>Sense of being in charge of decision.</p> <p>Her argument based on how she feels she is.</p> <p>No sense of needing to know about NIV yet</p> <p>She thinks the point she will need NIV is still far ahead. She feels that she is miles away from using the NIV? Is it because she is not breathing as bad as the man in a home? What is her measurement? When will she need it?</p> <p>Anxious is the reason for breathlessness.</p> <p>The real reason of referral remains uncertain to her, but she is confident of the outcomes. <i>I'm improved rather than her breathing being improved.</i> Is she including her feeling thereby she perceive her whole status got better? It's not only her breathing? Question the need of assessment</p>
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<p>necessary anymore.</p> <p>Yeah, because I'm just wondering about how you feel if they were to give you more information about the breathing and talk to you a bit more about the ventilator now?</p> <p>Well, they can tell me if they want.</p> <p>Yeah, so you wouldn't mind hearing about it?</p> <p>I wouldn't mind, but I'd rather not just yet, because, like I say, I'm not really at a place where I'm ready for all of that yet. I seem to be breathing even better now.</p> <p>So it makes a difference, how you feel things are, to how much you want to know about things, would you say?</p> <p>Oh yes, I think that's true now. Yes, I think that is true.</p> <p>But if the time came that you did feel your breathing had changed or that there was a problem related to your breathing - ?</p> <p>Well, yes, I would look into that more and I might try that and see if I felt it was something I could do. I suppose then, yes, that might be when I wanted to know a bit more about it all. But I don't mind going and having tests and seeing people, you know, I don't mind that at all. Maybe it is a bit different as well when you know there's something</p>	<p>The decision to follow information is up to her: sense of control</p> <p>She needs to be ready for an explanation about NIV, too. She is not convinced that she is needing NIV: 'yet'. <u>When her body is ready for the NIV?</u></p> <p>Defend herself by arguing her better condition to deny the need of NIV. <i>'Even': used to emphasise something surprising or extreme.</i></p> <p>Sense of being in charge of the decision</p> <p>Active information seeking Information then actual trial to make decision <i>'I could do': the sense of manageability?</i> <u>physical ability or mental to cope with it?</u></p> <p>Having test done is separate from initiation of NIV.</p>
<p>Timing of information; rather not just yet</p> <p>Readiness to NIV and information</p> <p>Better breathing</p> <p>Information and trial to make decision</p> <p>Manageability of NIV</p> <p>Having test and seeing people are ok</p> <p>Involvement of mask and NIV change the way she feels about test</p>	

	<p>involved there that doesn't sound very nice, you know, this whole, um, the mask and things. Maybe that does make it a bit different.</p> <p>Yeah, in what way?</p> <p>Oh just because, well, you'd want to put that off for as long as possible, having to try that, wouldn't you? [Laughs]</p> <p>Ah, would you?</p> <p>Course! [Laughs] But I'll go with whatever they tell me is best, you know, obviously, you know so I'll go for the tests and see. I'll go with an open mind – [laughs] a heavy heart but an open mind.</p> <p>Ah, right -</p> <p>If they want me to try it then I will, but I can't promise any more than that. I'll just wait now and we'll find out more when we get an appointment to see whoever we see about the breathing. But I'm not in any rush really, because it isn't causing me any bother.</p> <p>Yeah. Are you pleased that you know there is something to help you with your breathing, in case you did notice it changing?</p> <p>[Long pause] I suppose it is better than being fighting for breath, isn't it? Yes, I think it probably is good that there are things they can do to help you. That's my</p>	<p>Mask and things about NIV: <u>don't sound very nice. So, she wouldn't actually want to have her breathing assessed? Because NIV is involved? Although she thinks the result will be ok?</u></p> <p><i>She is trying to get an understanding by putting the interview in her situation: 'you'd want' expecting agreement.</i></p> <p><u>'Laugh' reasonable reasoning?</u></p> <p>Assumed common reaction</p> <p><u>Why does she say 'obviously'?</u> she thinks it's the best? Or is it an <u>general expectation for patients to listen to doctors?</u></p> <p><u>'Heavy heart': not easy to move? Need a lot of proof to convince?</u></p> <p>Although she has heavy heart, open mind allows her to consider NIV</p> <p>Try NIV if suggested</p> <p>No guarantee to accept NIV</p> <p>Emphasise no urgency</p> <p>No perceived problem thus no worry</p> <p>Excessive thought</p> <p><u>Breath is life so fighting for breath is fighting for life. Only breathing but nothing left. The worst scenario.</u></p>
<p>Hope to put NIV off as long as possible</p> <p>General expectation for patient to listen to doctors?</p> <p>Heavy heart but an open mind</p> <p>Try NIV if suggested</p> <p>No guarantee to accept NIV</p> <p>No urgency regarding NIV</p> <p>Breathing not causing problem</p> <p>Excessive thoughts</p> <p>NIV help her not to</p>		

struggle for breath Fear of being like the man	<p>fear with the breathing you see, ending up like the chap I saw, you know, really struggling.</p> <p>Yeah, that had a big impact on you?</p> <p>Oh it did. But like I say, I'm not quite there yet [laughs]. I'll just wait for this appointment, maybe find out a bit more of the situation and then take things forward from there if things need taking forward at all.</p> <p>Yeah -</p> <p>I suppose it's just uncertain what will happen. [Laughs] That's the thing of MND though; nothing's certain.</p> <p>Does that make it harder?</p> <p>Oh it does really; it makes it harder to make peace with things in your mind. It's shifting always, like, you know changing, getting worse and affecting different bits. And like this ventilator thing, well, I don't know much about it now but there's no way of knowing it will come to that. It makes it harder to plan and to decide about things. That's why I think I'll wait and speak to the doctor who deals with the MND breathing things. You'll come back when I've done that will you?</p> <p>I will if that's ok?</p>	<p>NIV to help her not to struggle. 'Fear': an unpleasant emotion caused by the threat of danger, pain, or harm. She doesn't want to be like the man</p> <p>Rather than talk about whether she needs the NIV, she illustrates herself to be yet away from the status where she needs NIV, or she has breathing problem? When does she think the time to start using NIV? Comparing with the man with MND? Why did she laugh? Perceived timing of the NIV</p> <p>She emphasise her suspicion of her needing anything. Is this actually the manifestation of her strong belief/ hope of unwillingness to use NIV?</p> <p>Uncertainty is emphasised by repetition.</p> <p>Nothing. Is it the same as everything is uncertain? Although she knew this man and she declared that she knew everything, but nothing is certain? She means she doesn't know when or what exactly are going to happen? So, gathering information is not really helpful?</p> <p>Stable status is essential to make peace.</p> <p>Always worse shifting not better. Shifting is caused when there is a further deterioration. So, is it possible to make peace in mind with a big change as long as it doesn't happen repeatedly? Is this just the frequency of changes?</p> <p>NIV out of blue</p> <p>Planning and decision difficult in always changing situation</p> <p>By planning, she probably means gathering information and decide.</p> <p>Medical consultation important when making decision</p>
Her current condition is not needing NIV Situation to be found out in hospital Dubious about possibility of needing breathing support Uncertainty MND: nothing is certain		
Uncertainty makes it harder to make peace Continuous negative shifting Unpredicted NIV Uncertainty makes it harder to plan and decide Consultation with the doctor essential in		

planning	Oh yes, I think I'd quite like to talk to you again. And I'll know more probably to be able to tell you what I'd like to do about it all.	Decision is to be made after enough information She doesn't want to argue much as she doesn't know much about it. <u>Proof is important?</u>
Current uncertain position regarding NIV	Do you think you're waiting for more information before making a decision?	Information important when decision is made She would cooperate with the healthcare team even before she has <u>information</u> She will try NIV for the hospital <u>She will be the ultimate one to decide if NIV is beneficial for her experience will also help decision making.</u>
Information important in making decision	I suppose I am in part, yes. If there's a decision to be made, it's always better to look into things properly. So, next time, I'll probably have more information. But I do think if they want me to try it, I will do that for them, and that's the best way of deciding, just trying it out and seeing for yourself.	<u>She doesn't like to be irresponsible of what she says?</u> Proof is important Persistent in her opinion about premature suggestion of NIV <u>She thinks taking advice from health people is important but she still trust her feeling most. Or her hope.</u> <i>If it happens: Not convinced of the possibility. almost denying or trying to black out the idea?</i>
Try NIV if suggested	Ah yeah, so you think maybe trying it for yourself would really help to make that decision?	
Trying out is the best way of making decision	I do really, yeah. I suppose it's no use you saying one way or the other and not really knowing about it. It's the proof of the pudding, isn't it? Yeah, I do think that. When the time comes though, which isn't now, it isn't time for any of that yet, but when it happens, if it happens, yeah.	
Trying as a proof	Yes, ok well, I think I've asked all of my questions now, and I think as you say there, we'll probably have a lot more to talk about once you've been across and spoken to [doctor2] and have got a bit more information about the ventilator.	
Premature concern on NIV and related things		
Not convinced of the possibility of getting breathing problem		

<p>Question on cure</p> <p>Lithium as a possible cure</p> <p>Dubious hope with lithium, but denied by a doctor</p> <p>Euthanasia</p> <p>Euthanasia rather than anything else</p>	<p>Yeah, I think that's right. I don't really know much at all about it at the moment, but when I do find out and I can say a bit more about it, I'll be sure to fill you in [laughs].</p> <p>Lovely. Well, before we end the interview is there anything that you would like to add to what we've said or anything else that you'd like to talk about?</p> <p>Um, no I don't think so. Other than, I did say to [doctor4], well, we were talking about a cure.</p> <p>Oh right?</p> <p>And I said to her 'What's the likelihood of a cure in my lifetime?' and I said 'In my lifetime, I can't see it' you know? But there is the lithium, you know, they're doing these lithium trials.</p> <p>Oh yes -</p> <p>And, um, that would enable me to do more - can't see how, but she said there was no cure and I think she knew where I was going with that. You know, I wanted to talk about the euthanasia thing.</p> <p>Right -</p> <p>So, I said I wanted to think about that rather than try anything else.</p> <p>Ok and what are your thoughts on that at</p>	<p>Question about the cure</p> <p>She can't see the cure in her lifetime</p> <p><u>'in my life time' to make sure that she would get a clear answer: h</u></p> <p><u>She wants to know black and white?</u></p> <p><u>Lithium: see uses present tense why not past tense? Is she considering about it?</u></p> <p>Dubious hope with lithium, but fact about the cure was mentioned by a doctor.</p> <p>Euthanasia</p> <p>Euthanasia rather than anything else</p> <p><u>Treatment and cure is different?</u></p>
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the moment - is that something that you think about a lot?

Euthanasia always at the back of her mind
Not thought much about euthanasia recently
Concerns on how she dies

Dignity rather than comfort
No wish to live any longer than she had to

Excessive thoughts
Fade away/ helpless thing

Real identity
Identity from how she lived
Denying the current self
Wish to finish

No wish for life prolongation
Disease decides her life span
Only cure matters

Ok, well perhaps I could ask then about treatments that might prolong your life - not slow the illness down but help you to live longer with it?

Oh I was thinking about it all of the time - it was always at the back of my mind.
But I haven't thought about it as much lately, but it is at the back of my mind still. I don't think I would want to just die like that, you know, slowly, so others around me had to watch me go. I don't care how comfortable they could make me - it's a thing about dignity. I wouldn't want to live like that for any longer than I had to.

Right -

I don't want to just [long pause] fade away, just a helpless thing. That really is just the worst thing that could ever happen to me; because, well, it must be hard for you to see it now 'cause you never knew what I was really like, but it's not how I've lived my life, like this, and I'm just so sure that it's not how I want to go out either. I want this all really to be over as soon as it can be; I wouldn't want to live much longer, and certainly I wouldn't want people trying to keep me alive longer than was natural - longer than the disease wanted me alive. So, if there's no cure, I don't want to be messing with anything else, you know?

Back of my mind: where matters seem to be dealt rationally.
Change in her thoughts with time

Thought on how she would be dying. Not exactly her death itself, but how.

'Just': what does she mean? Nothing more than just breathing?

Opinions of others also important?

'Had to' burden? Compulsory? They don't want to do it but no choice? Dignity: how she would be seen or appeared?

Who decide or what decide her life span? Her condition or her mentality?

Her perception of possible future: helpless thing

'thing' not a human being? She doesn't think she is not count as human being as she cannot do anything? Being able to deliver something makes us human being? Her question over her being?

Significant change and past real self

Denial of her new self. not accepted as self as explained as 'it's'

'Like this': almost detaching her condition? Separating her unwelcome change from her real self?

Denying and rejecting new identity

No interest in prolonging life

'Natural': so no euthanasia?

Disease holds patient's life. MND is personalised who vindicate how long patient should live.

Only cure matter

Living longer: burden Burden to herself and her family Upset	Oh I wouldn't want that, no, I don't think so. I think living longer would just be more of a burden, and not just for me but for my family [becomes upset – starts to cry]. I'm sorry.	Burden for herself is mentioned first, so that is more significant. <u>Becoming a burden is not a acceptable status for her considering how she describes her self: independent and actively approach the problems, but she has become a problem?</u>
Don't want to be helpless thing	No, no, it's ok, you don't need to apologise - I just don't want to die like that – you can understand can't you?	Appeal for understanding. <u>Want an assurance?</u>
Previous active life Denying the current self as herself	It's very difficult for you; I do understand that, I do. I was very active, you know? That's why. I'm not like this, this isn't me, you know? I'm not a sit around in a chair sort of person – I'm independent and strong and full of energy and full of life and laughter and doing this and doing that – helping other people; not having other people having to wait on me. I'm not an old lady sat in a chair dying [becomes upset]. My daughter goes mad you know, she won't tolerate this, me talking about dying, you know, my other daughter understands that. They know it's what I want, but my daughter doesn't agree with it. But it's my choice isn't it? It's something I've given a lot of thought to.	Past identity Opposite new identity from the past upsets her. <u>She explains how she really is in present tense which shown that she sill sees herself in that way so not accepting the changes. Also she argues that she is full of life without MND, so she lost that with MND?</u> <u>Reject accepting the changes as her identity</u> <u>Doing nothing seems very upsetting as she mentions twice. The picture resembles those in a nursing home. 'The typical elderly'?</u>
Previously independent/ full of life and energy/ helping other		Understanding from her family is important? Support with understanding. <u>No understanding could generate stress?</u> Choice as her right. Excessive thoughts
Denied self: old lady dying in a chair No understanding from her one daughter Understanding from the other daughter Her right of dying choice Excessive thoughts on her dying	And you say you've shared these thoughts with [doctor4], when you spoke to her? Yes, she knows I'm sure how I feel. It's just been something on my mind for a long time.	'Mind' a place where important thing is addressed and processed. <i>'mind': the element of a person that enables them to be aware of the world and their experiences, to think, and to feel; the faculty of consciousness and thought.</i>
How to die in her mind		

Dying process it the thing to be considered in the future

Help appreciated as long as she feels she can keep going
Acceptability of her status to herself

No more help if she is not happy and becomes a burden

Open mind

Possibility of future change in her attitude

Just have to wait to see the future

And it's still on your mind?

Oh yes, I think it is really. It's just there, I think about it every now and again; just about when the time comes. I don't think now, but I think in the future. I just thought that I should let you know that, just because it's something that I told to [doctor4] and it's something that I still think is true and I still think is important.

Do you think that view changes how you feel about certain things, um, like treatments like the ventilator?

Well, I'm very happy for people to help me as long as I feel I'm able to keep going in a way that, um, that's, well, that's acceptable to me, you know, that's not, well, I always just think if I get to a point where I think I'm just being kept alive and I'm not happy and I'm just a burden on the girls, then I wouldn't want any more help.

Right -

So, it is a consideration for me to have - it's always a thought in the back of my mind. But we'll just see how it goes. I'll not commit myself to anything because I want to see how I feel about things as time goes on - as the MND goes on and gets probably a lot worse than this. So, well, we'll all just have to see what the future brings.

When is the time to think about it?

Help appreciated as long as it is ok with her

Acceptable. Her dignity seen by herself
'Always': again illustrates how often she thinks about it.

Help is what she sees as a help. Susceptible to subjectivity.

Open mind
Not bounding herself up with a premature decision.
Freedom also important aspect for her?
Her feeling is important
Time influence
MND influence
What future brings: no control over the future

MND only brings more bad changes Hope for time Uncertainty of the future Just hope for the future	<p>Yeah -</p> <p>I just wish it were bringing something good, but it won't be. It'll just be bringing more changes and things I can't do probably. But, let's just hope that it won't all go downhill too fast; you know, that it doesn't happen quickly. Especially with the breathing, let's hope I'm still doing alright when I next see you. You just don't know, but you can keep your fingers crossed for that much [laughs].</p> <p>Well, I'll very much look forward to talking to you again then.</p> <p>Oh yes, it's been very nice to talk to you - quite helpful actually to say things, funny that really. Oh and yes thank you for listening to me, I hope that was alright to talk about?</p> <p>Of course, you're very welcome to say whatever it is that's on your mind.</p> <p>Oh right, good then.</p> <p>Ok, well shall we end the interview there or - ?</p> <p>Yes, I think so, I think I've said everything now - even more than I thought I would.</p> <p>Ok, well, in that case I'll say thank you very much - and thank you for being so honest with me and sharing all of your thoughts on these things. I know it's not always easy to</p>	<p>(More changes which negatively affect peace in mind.)</p> <p>Hope: what human beings seek for.</p> <p>Metaphoric expression of downhill illustrates no recovery, but only going worse till it hits the bottom. So, patient is describing there is no way of going up, but the process may be slowed down. Although she wants it to finish as soon as possible, her current condition is not bad and she has something to hold her back and hold onto life?</p> <p>Uncertainty Sense of end of life?</p> <p>Her experience with daughter made her to ask interviewer if it was ok?</p> <p>Being listened to is helpful. But didn't think it would be?</p>
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Her daughter won't listen to her honest feelings	<p>do.</p> <p>Oh thank you. It's what I want to say you see? I mean my daughter won't hear it, but it's what I really think; what I feel about it. So thank you for listening to it.</p> <p>Oh well, you're welcome. I shall just switch this recorder of now then if that's ok?</p> <p>Ok, yeah.</p> <p>[END]</p>	Being listened to is important.
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Catherine:

Coping Strategies

Hope

- Holding onto hope before official diagnosis
- Hope as a human nature
- Hope for time
- Just hope for the future

Active approach to information

-For loopholes

- to find loopholes

-To control

- Control by a way of getting information
- Previously thought MND manageable?
- Information for preparation
- Information to slow things down

-For decision-making

- Information important in making decision
- Attempt to get clear picture of MND
- Uncertainty makes it harder to plan and decide
- MND: nothing is certain
- Uncertainty of the future

Information

Nature of information

- No good aspect of information
- No hope from information

-Impact of information

- Wanting to know but regret to find out
- Avoid attitude towards information seeking
- Agony with information on MND
- Ignorance is better than knowing what to come
- Being fed up with information and MND
- No more information and MND

Impact of knowledge on MND

-Knowledge from previous job

- Victim of her previous job
- Clear path of the illness from her experience
- Excessive thought on prognosis
- Knowledge on breathing problem from her old job

-Unexpected devastating diagnosis

- Her symptoms different from her MND knowledge
- Questions on getting MND
- Diagnosis shocking
- Diagnosis devastating
- Not expected diagnosis

Changed attitude

- Negative impact of information
- Reluctant to prepare: horrible
- Change in other's daughter's information seeking attitude

- Preference of not knowing breathing problem

MND

MND : stream train

- Empowering of MND
- MND path
- MND only brings more bad changes
- Her symptoms as evidence on MND
- Continuous negative shifting

Controlled by MND

- MND as another being which grows and reveals
- Disease decides her life span
- MND; controllable/not controllable

Question on cure

- Dubious hope in lithium, but denied by a doctor
- Only cure matters
- Drop foot fixable
- Pointless preparation

Breathlessness

Causation of breathlessness

- A bit of depression caused breathlessness
- Anxiety to be blamed for her breathlessness
- Effective anti-depressant
- Breathless problem solved by anti-depressant
- Causation of breathlessness: doing too much, upset

Unproblematic breathing

- Breathing is quite good
- Improved breathing
- Comfortable in bed
- No complain on her breathing
- No more breathlessness
- Perceived recovered breathing
- Not upset with breathing

No worry over breathing

- Optimistic view on her breathing
- Having test and seeing people are ok
- Her breathing is ok so test will be ok

Significance of breathing

- Breathing especially frightening about MND
- Breathing is cruel thing
- Breathing is curious thing
- Usually ignored of the significance
- No life without breathing

Link between breathlessness and the terminal phase

- Gentleman hanging on to life by breathing
- Fear of being like the man
- Observation of man fighting to breathe
- Doesn't want to fight for breathe and cling on to life

NIV

Readiness to NIV and information

- NIV information not yet as her breathing is better
- Timing of information: rather not just yet
- Unpredicted NIV
- No definite of the course of breathing

Suspicious about the need of NIV

- No sense of needing to know about NIV
- Sense of premature assessment of her breathing
- Breathing test maybe not exactly necessary
- Not convinced of the possibility of getting breathing problem

Possible interest in the future

- Heavy hearted but and open mind
- Just have to wait to see the future
- No objection with breathing assessment
- Possibility of future change in her attitude
- Future plausible interest in NIV information
- Not enough knowledge on NIV

Impression

-Mask

- Having something on your face
- Doesn't sound very nice: having mask on
- Scary to have something on the face
- Imaginative claustrophobic mask

-Permanent nature of NIV use

- NIV would become a must-have item
- Regular interval of air blow
- Uncertainty of her ability to deal

-Uncertain acceptability of NIV

- Hope to put NIV off as long as possible
- No guarantee to accept NIV
- Manageability of NIV

Trial

NIV trial for medical staff

- Try NIV if suggested
- General expectation for patient to listen to doctor?
- Situation to be found out in hospital

For decision making

- Trying as a proof
- Information and trial to make decision
- Trying out is the best way making decision

Self

Previous self

- Previous active life
- Previously independent/ full of life and energy/ helping others
- Real identity

New self

- Fade away/ helpless thing
- Burden to herself and her family

Change to previous self

- Upset
- Misunderstanding from others: drunk
- Denied self: old lady dying in a chair
- Denying the current self as herself

Autonomy

-Acceptability and dignity as important factors

- Living longer: burden
- Dignity rather than comfort
- Help appreciated as long as she feels she can keep going
- No wish to live any longer than she had to
- No more help if she is not happy and becomes a burden

-Regarding the way to die

- Her right of dying choice
- How to die in her mind
- Euthanasia always at the back of her mind
- Dying process is the thing to be considered in the future
- Wish to finish
- No wish for life prolongation

-Importance to be heard

- Understanding from the other daughter
- No understanding from her one daughter
- Her daughter won't listen to her honest feeling
- Being listened to is important
- Repetitive visit to her doctor
- Know you own body

-Outcome of neglected autonomy

- Frustrated and worried as results of mistreat from her doctor
- Think back about her doctor makes her upset

Preservation of the Self		Extracts
Themes		
Identity		
<i>Damaged identity</i> Catherine:	I don't want to just [long pause] fade away, just a helpless thing. That really is just the worst thing that could ever happen to me; because, well, it must be hard for you to see it now 'cause you never knew what I was really like, but it's not how I've lived my life, like this, and I'm just so sure that it's not how I want to go out either. I want this all really to be over as soon as it can be; I wouldn't want to live much longer, and certainly I wouldn't want people trying to keep me alive longer than was natural – longer than the disease wanted me alive. So, it there's no cure, I don't want to be messing with anything else, you know? P11	
Matthew:	I've always had a shave every day of my life I have. I think that might be the worst thing about this motor neurones'.	
Simon:	I always used to wear a shirt – had to, you know, had to be smart, take care, look good. Always used to wear a shirt every day and have a shave and now I can't. I have to wear tops without buttons and I hate that. It's not really me anymore because of what I can't do – the fiddly things like buttons. In business, it's important, you know, dress the part – not like this, I hate this now that I'm wearing.	
Preservation		
<i>Autonomy</i> Catherine:	I just don't think I would like that, because as well, it's not just for a little bit, it's not like oh you're ill and you need to use this mask for a little while, you know, it would be for you to help you to breathe for the rest of your days then. It would end up being a permanent thing of you having to use it. I don't think I want that really. I'm not sure I would be able to just deal with that.	
Simon:	I don't want to end up like one of those people who just lives hooked up to a machine. They're not really living, I wouldn't want it to be all of the time and not have any life. When I first heard it – that was what I thought. That was my first thought when I heard it. That's what I'm afraid of – if I start on that a little bit. [Long pause] I don't want that. You can't do anything.	
Matthew:	I wish I could still do that myself, but you know, a lot of things I can still do, it's just some things I can't do now, like, um, like tucking my shirt in.	
<i>Dignity</i> Catherine:	I don't think I would want to just die like that, you know, slowly, so others around me had to watch me go. I don't care how comfortable they could make me – it's thing about dignity. Well, I'm very happy for people to help me as long as I fell I'm able to keep going in a way that, um, that's, well, that's acceptable to me, you know, that's not, well, I always just think if I get to a point where I think I'm just being kept alive and I'm not happy and I'm just a burden on the girls, then I wouldn't want any more help.	
<i>Quality of life</i> Ian:	And that doctor what's-his-name, um, [MND patient], well, but look at the state he's in. What kind of a life is that? I mean his brain is still alright; that's still alive, but that's all though.	

Breathing <i>Significance of breathing</i> Catherine:	<p>I remembered him this chap, you know, I remember his, um, he was really breathless almost all of the time in the end, towards the end, and fighting, you know, really fighting to breathe sometimes actually – hanging on to life really I suppose, you know, despite all how he was the rest of him. That surprised me actually. So, um, what I thought was that I didn't want to end up like that gentleman in the home, fighting for breath and clinging on to life like that.</p> <p>I don't like the thought of my breathing being done by a machine – machinery helping me to breathe. That's day <i>or</i> night. [...]It's just the idea of it. It's like your body really doesn't work properly then really [- unclear].</p>
<i>Autonomy of breathing</i> Catherine:	<p>I just don't think I would like that, because as well, it's not just for a little bit, it's not like oh you're ill and you need to use this mask for a little while, you know, it would be for you to help you to breathe for the rest of your days then. It would end up being a permanent thing of you having to use it. I don't think I want that really. I'm not sure I would be able to just deal with that.</p>

Personal Perception of Intervention with NIV

Themes	Extracts
Image of the features of NIV <i>Mask</i> <u>Sound</u> Catherine:	Oh it just seems a bit; well it's scary having something like that on your face I think. And I'd imagine it's quite claustrophobic as well; yeah, just having to wear that thing – doesn't sound very nice to me.
Simon:	Just [long pause] having it on my face. But maybe it won't be so bad.
<u>Alien</u> Ian:	I told Dr.1 at first when I saw it I said, “no way that I can stick the mask on my face”. I said, “ foreign, alien”... I just couldn't do it.
<u>Appearance and practicality</u> Matthew:	I know I didn't like that mask first off, I thought I'd feel a bit silly with that on. And when I had that on, I couldn't talk see, so everyone was talking all around me but I couldn't join in 'cause I had this breathing mask on.
<u>Claustrophobic</u> Timothy:	Did you consider what benefits the ventilator might give you when you made the decision? [Nods head] Spells: M – A M - The mask? [Nods head] You just thought about the mask? [Nods head] And was it specifically the claustrophobia with the mask? [Nods head] That was the only think that really mattered to you at that time? [Nods head]
Ian:	Well, that and the thought of actually having to out that thing on my face. It's just the thought of it, it being there, something on my face. I couldn't sleep with that on. I just know I couldn't sleep.
Ted:	You know some people trap when they go into dark place or somethingg like that people... what's they – claustrophobia – I just don't want it... I don't want it on me face anything on me face.

<i>Air Pressure</i> <u>Shocking</u> Matthew:	Don't it blow? My god! I didn't expect it like that. I thought it was less air type of thing. I didn't expect it to be so.... it was really blowing. I think I said to you didn't I?
Rachel:	Yeah. Too strong for me the ventilator.
Reaction to NIV <i>Fear</i> Matthew:	But it did make me feel sick and you can't have the machine on like that can you, you can't ruin it can you, you see, that's why I'm frightened. I didn't actually be sick, but it made me feel like I would be. So, I thought I wouldn't use it – better not. I didn't really like that. It might be me it just something - more or less frightening you know it's um... this thing on your face trying to throw it away and things cause I haven't been a good sleeper all me life I'm always turning over and turning over. I just said it was awful yeah. I thought it was a frightening experience.
Ted:	I tried... I tried the mask on. I couldn't even without being connected. I couldn't even stand that. It has to come off.
<i>Unbearable</i> Ian:	I won't be able to try and live up with that mask. I can't sleep with that on me face. No way.
Belief <i>Unable to wear the mask</i> Ian:	You thought that you would feel claustrophobic in the mask? [Nods head] Right and had you experienced any claustrophobia before that made you think it might be a problem with the mask? [Nods head] Has that been something you're had throughout your life? [Shrugs] You just thought that it would affect you if you had to wear a face mask? [Nods head] And was it only the claustrophobia that was a concern to you? [Nods head] There were no other factors? [Shakes head]
Timothy:	I thought 'Well, this is making me worse not better' that's what I thought you see. But I don't have to use it if I don't need it or if it makes me feel worse.
<i>Machine worsen the condition</i> Matthew:	

Threats

The loss of control

Ian:

Keep trying, keep trying. I know it'll do me good eventually, but just... I just couldn't... I just couldn't handle it really.
This is not for me. ...(unclear) face... KGB torture. [shrug laugh]

Matthew:

And when I had that on, I couldn't talk see, so everyone was talking all around me but I couldn't join in 'cause I had this breathing mask on.

Ted:

It's just [pause] as if though it stopped me breathing as though I was trying to breathe out and this was blowing back and the wind was blowing out [exhale].

Rachel:

Yes it was forced.... That's what it's like when it winds it's like, you know what I mean, it [unclear] can't breathe. [becomes upset]

Negative Experiences with Healthcare Service

Themes	Extracts
Impression of hospital <i>Dislike of hospital</i> Ian: Matthew: <i>Poor image of hospital</i> Ian: <i>Preference of peaceful environment</i> Ted:	<p>I just really have never liked the.</p> <p>I didn't want to stay in the hospital. You know I don't like hospitals don't you?</p> <p>They're places where you go when bad things happen really aren't thy? You know, when you're not well and people are dying and things. So, I mean I just don't like them. Never have.</p> <p>[overlapping with carer] not wanting for mixing or anything a bit of alone type of thing, In a hospital I get frightened of hospital again the all set up you know so...</p>
Bad interaction with hospitals and its outcomes <i>Emotional damage</i> <u>Withdrawal</u> John: Peter: <u>Rejection</u> Peter: <u>Confusion</u> Ted: <i>Disempowerment</i> <u>Invaded autonomy</u> Ian: <u>Loss of control</u> Simon:	<p>When asked about breathing tests he was reluctant to talk about the, He confirmed that this was related to his experience at the hospital when prompted. He agreed that this had not been a very enjoyable experience for him and had put him off future visits.</p> <p>If you were given another appointment – if it was <i>guaranteed</i> that it wouldn't be cancelled this time – would you be willing to go and have the assessments there?</p> <p>Patient gestures an emphatic 'No', crossing over his hands in a definite gesture of 'it's over'.</p> <p>I was agreeable at first but every appointment since 2006 has been cancelled.</p> <p>you don't realise what's happening because I thought I'd done something wrong.</p> <p>Hmmm, yeah. They' re trying to persuade me, yeah, very much so. I know they're all at it, trying get me to change my mind – even thought really I think it's my decision. And I have tried to tell the,, I do say the same thing every time I go there.</p> <p>Well... they all forced on me, really.</p> <p>they're all trying to force me on to it and I, well, I already made my mind up a long ago – they don't seem to take much notice what I'm saying.</p> <p>I'm tired of it all already. And it's going to get worse – I don't need all of it. I wish they'd left leave me alone. If I haven't [long pause] if I haven't got long, I don't want to spend my time like that.</p>

Not Needing NIV

Themes		Extracts
Changes	<i>Breathing</i> <u>No change</u> John:	When questioned about his breathing he felt that he had not experienced any change in his breathing and was not having any problems at all.
	Timothy:	And had you noticed any changes in your breathing when you were offered the ventilator? [Shakes head]
	<i>Change</i> Catherine:	I do get slightly breathless if I have to do too much, and if I get upset, but actually it doesn't cause me any problems or any worry or any kind of, um, it doesn't upset me.
	Ian:	I'm breathless.
	Matthew:	It's like that a bit with the breathing as well, some days I feel better than others
	Simon:	Well, sometimes I can get a bit breathless if I try and stretch myself. If I try to stretch myself it can get breathless – that is true.
	<i>Sleep</i> Ted:	Cause I said... It should be a good day you know cause that's the reason sometimes I can't sleep you know me nose is blocked up, but since I [unclear] clear me I didn't...
	Rachel:	Ah, ok. So, you are not having disturbed night. [patient's voice getting weaker] Well, I do but it's because of me arm.
	<i>Denial?</i> John:	When questioned about the previous symptoms at night mentioned by his wife he denied knowledge of these.
	No significant changes <i>Different causation</i> Catherine:	I mean actually my own breathing is quite good; I do get slightly breathless if I have to do too much, and if I get upset, but actually it doesn't cause me any problems or any worry or any kind of, um, it doesn't upset me. I mean, I'm usually just sat here during the day or I'm in bed and it doesn't cause me any problems here or in bed, I'm quite comfortable in bed. I mean, the reason I think they wanted to check my breathing was because I was having this little bit of breathlessness - but since [doctor 4] has started me on these anti-depressants, actually It's almost completely gone.
		When I'm breathless, you know, it's because my legs start going you see, then I'm breathless
		Matthew: What I'm worried about is when it gets summer, if it's too hot. I don't like it when it's hot; that makes my breathing go worse. Trying to put my shoes on or my trousers on, that takes my breathing.

Ted:	When I... I don't think I needed to use it because I put it down to a bit of like stress – we had a lot of troubles with neighbours and I thought that was doing a lot to it you know cause I was all worked up... and all night along everything you know and I thought that was stopping me sleeping and everything. Well it did didn't it [carer]?
Rachel:	I'm lying on me arm and it starts hurting that's why I have to... I wake up to move me arm [voice getting weaker].
<i>Luck</i> Matthew:	' because they did these overnight tests, but what if they were just one of my bad days and the rest of the time I could be alright, couldn't I?
Ian:	I just thought I'd check it out, You know, I go in and see all these people and they do these tests, but I could just have them on a bad day
<i>Evidence of stable breathing</i> Ian:	Oh no, that's fine. It's very stable – according to that [points to peak flow meter that he had shown to researcher prior to interview].
<i>Solution for the changes</i> Simon:	But I have a spray for that, to help me if I feel my breathing is slightly short. I have a spray for that. So, because I can use that, I don't have any concerns at all about my breathing really.
Suspicious about the need of NIV Catherine:	But I'm improved since then, so I suppose it might not be exactly necessary anymore.
Ian:	So, I don't know about that they're saying about my breathing over there at [hospital].
Matthew:	So I don't know about all these new things coming to me.
Ted:	cause in me own mind I don't think I need it you know.
Rachel:	I don't feel as though I need it at night. I'm [unclear] sleeping pretty well.
Comments from doctors Simon:	But actually – actually, she only sent me for these tests as a precaution – it was a precaution, because of my swallowing wasn't very good, so to make sure, she sent me to have breathing tests.
Ted:	I don't think so, but [doctor 1] said it's the start of it. He said more less not that you don't want it to but you... you know you... you need in time you know this isn't for now but supposing time you might needing it type of thing.